

SIGNATURE PAGE

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ABSTRACT

This Phenomenological investigation explored how an adult with Asperger's syndrome experiences his or her special interests. Research participants consisted of 12 individuals, eight male and four female. Each had been diagnosed with Asperger's syndrome by a qualified mental health professional and each participant had identified having a special interest. Upon analysis, the following themes were identified: the three textural themes are 1) coping, with the sub themes of escape and anesthetizing, focused attention, and maintaining predictability through object focus, 2) addiction, 3) valued and respected. The primary researcher provided three individual textural descriptions, three structural descriptions, a composite textural and structural description, and a synthesis integrating the above. Two elements of the study appear to be unique findings, and therefore provide a new contribution to the understanding of special interests. This study reveals that males appear to be more intensely absorbed in their special interest than females. In addition, clear differences emerge between special interests and Obsessive Compulsive Disorder. Special interests are used as an ego syntonic coping mechanism and as a bridge to social connection. The findings of this study suggest the value of further research in utilizing self-reports garnered from unstructured in-depth interviews with adults with AS about their special interests.

DEDICATION AND ACKNOWLEDGEMENTS

I dedicate this work to people in both my past and present, which includes my mother and father for their support, my professors and guides, especially Drs. Katz, Rubin, and Scott for their unwavering belief in me. I would like to acknowledge Dr. Fran Brown for her editorial love and guidance. Also, my friend and inspiration, Nick Dubin who helped me develop the passion for my question. To my classmates Deborha Cambell, Collette Simone and Miriam Engstrom, who became my cheerleaders and friends. And to my husband, who was relentless in his wish that I “check it off the list.”

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CHAPTER I

Meaning of the Research Question

The beginning sections of this chapter explore the personal and professional relevance of this research. The latter portions state the research question and define the terms of the question. Finally, the social meaning and context unique to this phenomenological study are discussed.

Personal and Professional Relevance

My desire for understanding more about these special interests is to assist me in promoting a strength-based therapy approach for people diagnosed with Asperger's syndrome and autism. This journey began many years ago.

I pulled into the driveway of my client's house; it was a routine visit. I had been contracted by the family to come to their home once a month to teach the parents how to work with and relate to their 5-year-old child, recently diagnosed with Asperger's syndrome (AS). As I stepped out of the car, a smile spread across my face. I was envisioning the next few hours I would spend with Kevin and his family. The topic of the session was predetermined: Kevin's interest and passion for vacuum cleaners. To enter into his world, I allowed myself to be immersed in an intense crash course that included conversations revolving around the pros and cons of a Hoover versus a lightweight Eureka brand, which Kevin preferred. We talked about the purpose and effectiveness of different hose attachments and which brand offered the most features. Invariably, all three of the vacuums wound up on the living room floor as Kevin demonstrated his vast knowledge and comprehensive understanding of the operating manuals that came with each of his prized possessions.

I was a novice on the topic of vacuum cleaners. I never read the owners manual for my vacuum cleaner, so I had many questions. Kevin never became impatient or talked down to me when I posed clarifying questions like: "How can you tell the difference between the suction power of a Eureka over the more industrial models?" Kevin kindly informed me how to determine the appropriate vacuum cleaner based on the surface being addressed and the actual contents that needed to be removed. There are many variables that need to be taken into consideration. As he put it:

You can't make a snap decision about which cleaning device to use. There are issues to be considered. One vacuum cannot be expected to deal with every mess . . . each model is unique and has special qualities that would make it the appropriate choice for cleaning up one situation, but not another.

Kevin's parents watched me closely as I listened and engaged with their young son. Most people who came to their house would stare at Kevin with their mouths hanging open as he began his monologue or script about his passion. They would politely listen for 10 or 15 minutes and then excuse themselves, often never coming back to engage with Kevin. They made comments like: "What an odd young boy you have," or "Looks like you have raised yourself a vacuum engineer," and "He should get out more and play with other kids his age."

I was one of the first people Kevin's parents met who sat and listened to him. Not only did I listen, but I also engaged and encouraged Kevin, and we quickly became fast friends. I sat in awe of this little boy whose interest in a topic made him an expert on a subject at the age of five. I began to gain a new appreciation for my vacuum cleaner and the amazing things it was designed to do. Because of Kevin, vacuuming, which had once been a chore for me, became a positive experience. After knowing Kevin, I have never walked by a vacuum cleaner without smiling.

I work with children and adults whose brains function differently. While most clinicians focus on their clients' impairments and deficits, I seek out the parts of the brain that are working or intact. I build on the individual's strengths to address their challenges. I believe that the special interests, where individuals with Asperger's syndrome amass encyclopedic amounts of information on a particular topic such as the civil war, vacuum cleaners, coins, road maps, or the flush capacity of toilets, are manifestations or proof that specific areas of their brains are intact or compensating exceptionally well.

One unique characteristic of people diagnosed with autistic spectrum disorder is their ability to focus on specific areas of interests. I am fascinated by these individuals' unending desire to inquire, research, read, and discuss all aspects of their special topics with boundless enthusiasm and joy.

Very little has been understood, researched, or discussed about the special interest areas associated with Asperger's syndrome, yet the diagnostic weight placed on special interests is significant. To be diagnosed with Asperger's syndrome, an individual must have a history of intense areas of interest, fixations, or obsessions. Yet there are few studies that explore the way in which special interests are selected and what these interests mean to the individual with Asperger's syndrome.

Many psychotherapists and other professionals view the special interest as a liability. "He is obsessed with the computer," "He is constantly correcting the history teacher," or, "He only wants to discuss the train schedule and never asks about my interests," are commonplace complaints and grievances made by people who engage with individuals diagnosed with Asperger's syndrome. While these statements can represent valid concerns, I see the preceding commentary as missed opportunities for connections.

It is my hope that by pursuing a deeper understanding of this phenomenon through in-depth interviews of adults with Asperger's syndrome, I will contribute an optional and positive way for parents and professionals to view and understand special interests.

In all my life, I have never experienced anything as passionately as Kevin was about his vacuum cleaners. I admired him. Think of the things I could learn if only I had the motivation to read endlessly and research a particular topic. I felt like a person without a purpose compared to Kevin, who so clearly knew what could bring light and joy into his life.

One of the negative aspects of people diagnosed with Asperger's syndrome is their lack of social reciprocity or difficulty with the back and forth flow of natural conversation. While Kevin loved to discuss his vacuum cleaners, he never inquired about me or sought my opinion. His social interactions had the flavor of a monologue rather than a dialogue.

As I reflected upon this fact, I began to consider how my past relationships prepared and shaped me to do the work I do today. I grew up in a complicated home and had an older stepbrother with a host of psychological issues. He was and remains socially isolated. He has a long history of intense special interests and difficulty relating to others, and has never been able to hold down a job for a significant period of time. His pattern of relating is quite strange and most people find themselves feeling uncomfortable around him. As a young child, I tried hard to make a connection with my older brother, but this proved quite difficult. I tried to join him in his special interests, which during the time of my childhood included topics such as music, movies, and history. The eight year age difference made it hard for me to engage with him at his high level. It is probable that my

interest in the Asperger population, a group that shares much in common with my older brother, is an attempt to connect with men and women who shared a bond with my sibling. My sadness at never being able to develop a relationship with my brother has probably influenced and driven my specialized niche.

I was acquainted with a neighborhood boy who was much like my brother. That relationship most likely impacted my decision to work with the Asperger population as well. I remember that from an early age, I stared out the front window of our family living room. The view outside that window was our neighbor's front lawn. The neighbors had a son six years older than me, and I was transfixed by him. He, however, was transfixed by something he called "etersions," and later the sprinkler system. Etersions were essentially mud pies he created and placed in glass jars or buckets. He put insects in the mud solution and watched them as they succumbed to a horrible death by drowning. He liked to watch the process they went through as they sank, and noted that insects died in unique ways.

The neighbor boy had a second dominating interest that revolved around the irrigation system in his yard. This took up the rest of his time. He spent hours dissecting each sprinkler head and studying the individual components and how they worked. He studied the sprinklers and happily explained how the system functioned to anyone who passed by.

I watched him from afar for years and was always willing to ask questions; I sat for hours and listened to complex discussions on his latest fascination, which went on to include copying down license plate numbers (he accumulated thousands), playing *Dungeon and Dragons* and other board games, making movies, and writing screenplays.

There was always an obsessive quality to his interests that made him different from the other kids. His way of relating was very one-sided. He never really wanted to know about me, but he was always willing to demonstrate his knowledge about his particular area of interest and I was always interested.

Looking back, I wonder why the lack of social reciprocity did not bother me more. In hindsight, I realize now that I appreciated the straightforward and rather one-dimensional aspect of our relationship. Because the situation in my household was so confusing and unpredictable, I craved sameness and predictability. I never felt he disliked me, or liked me for that matter; rather, his own interests were so pressing and important that he needed to give them his total attention.

I was drawn to working with the autism population for a reason. My past played a role in my career choice. I often find comfort in simplistic one-sided interactions and relationships others would consider unfulfilling. Yet that is not the only reason I chose this professional niche. Passion is the other aspect that draws me to the work. The children and adults I know with Asperger's syndrome have a passion for their unique topics that is unparalleled. Often children with AS have above-average IQs and they are gifted and talented in many aspects relating to their special interests. Their passion and intelligence was something I admired and coveted. I was diagnosed with learning disabilities as a child and academics were a struggle. I thrived socially but acquiring new knowledge was not something that came easily for me. My attraction to people, especially my brother and the neighborhood boy, was in part motivated by my desire to unlock the mystery of learning that was shrouded by my own inadequacies. My hope was that if I was liked by people I considered gifted, I would be considered smart by

association. Daily, I observe and listen to numerous accounts of young children diagnosed with AS who can spend 10 to 15 hours engrossed in reading, writing, and researching aspects of their specialty topic. I have never felt so impassioned or motivated to commit my time and energy to anything of this nature. I admire and sometimes envy my clients' desires to amass and memorize large amounts of information. Yet when you read the AS literature, special interests are often considered as a way to compensate for impaired central coherence.

Frith (1989) terms this highly focalized attentional ability as “. . . stimulus over selectivity” (p. 107). The concept of stimulus over selectivity is considered a problem of central coherence that affects those with autism. Frith states, “Some high-level component in the mind has to decide what in the mass of incoming sensations is worth attending to.” She explains:

A good decision would be based on large amounts of pooled information. If coherence at this central decision-making point is weak, then the direction of attention would be quite haphazard. What form would this take? We would not look for poor, but peculiar attention. (p. 107)

Frith believes over selectivity can be caused from stimulus overload or under stimulation. She describes a boy with autism whose fixation with drapery began when he was forced to watch plays at his school. The content of the productions eluded him; he quickly became bored and his attention was drawn to the stage curtain. He went on to become fascinated by the ripples and curves continually changing under the spot light. This interest evolved into a life long fascination with stage curtains. This evolution of special interests appears to be linked to a weakened central processing system. Moreover, the literature attributes the special interests as an attempt to manage an overwhelming or under stimulating environment.

Frith (1989) states, "Experimenters are continuing in more sophisticated ways to identify the nature of information processing problems in autism" (p. 106). If I have found a way to channel my negative energy around my damaged childhood relationship with my older brother and my learning disabilities into a positive career, is it possible to look at the special interests in a constructive way in order to better understand and motivate a person diagnosed with AS? Very little has been understood, researched, or discussed about the special interest areas associated with Asperger's syndrome.

Statement of the Research Question

I believe special interests serve as an opportunity and way to engage, relate, and interact with a person diagnosed with Asperger's syndrome; therefore, I have decided to pursue and investigate the question: *How do adults with Asperger's syndrome experience their special interests?* It is my hope that by pursuing a deeper understanding of adults with Asperger's syndrome, I can gain new perspectives and insight into the nature of children and adolescent experiences. Therefore, my research can contribute more positive options for parents, professionals, and people with Asperger's syndrome through which to view and understand special interests.

Definition of Terms

At this stage, it is important to clearly define the terms of the research question. Defining the primary words will guide and refine the intention of the investigation into this topic. The terms that will be defined are *Asperger's syndrome*, *special interest*, *adult*, and *experience*.

Asperger's Syndrome

The American Psychological Association's diagnostic manual (APA, 2000) defines Asperger's Syndrome as:

. . . severe and sustained impairments in social interaction and the development of restricted, repetitive patterns of behavior, interests and activities. The disturbance must cause clinically significant impairment in social, occupational or other important areas of functioning (p. 80).

The diagnosis of Asperger's syndrome did not appear in the APA's diagnostic manual until 1994. The syndrome was named after Asperger, a Viennese pediatrician. In his doctoral thesis published in 1944, Asperger characterized four boys noted as being highly unusual in their abilities to relate socially, utilize language, and function cognitively. Asperger utilized the term *autistic psychopathy* to describe the attributes of the four boys he considered to be suffering from a schizoid or schizotypal personality disorder.

In 1943 Kanner, a child psychiatrist, published an article describing curious behaviors he observed in 11 children he worked with at Johns Hopkins Hospital. Both Kanner and Asperger described symptoms and behavioral patterns that had many commonalities. Kanner went on to call these strange behaviors he observed *autism*, the Greek word for *self* or *auto*, because the children seemed aloof and removed from the world around them. Kanner classified autism as a subset of childhood schizophrenia.

Unfortunately, almost 40 years passed before Asperger's research was translated into English by Wing. Wing was seeing an influx of children diagnosed early on with classic autism who later developed fluent speech and abilities to socialize. This group also demonstrated supreme intellectual functioning in areas of special interests. Wing elaborated upon the findings and observations Asperger made and characterized the

disorder as a continuum that ranged from children who were profoundly impaired, to the gifted, with many shades of gray between.

Attwood (1998) quotes Wing in listing the primary clinical features of Asperger's syndrome, including: “. . . lack of empathy, naïve, inappropriate, one-sided interaction, little or no ability to form friendships, pedantic repetitive speech, poor non-verbal communication, intense absorption in certain subjects, clumsy, ill coordinated movements and odd postures” (p. 15).

Kluth (2003) characterizes Asperger's syndrome as a label given to people who communicate differently than others, have difficulty with transitions, and are absorbed by fascinations or fixations. She also discusses the strengths associated with Asperger's syndrome, citing superior rote memory and an interest in math and sciences.

While Asperger's syndrome was once a completely separate diagnosis from autism, it is now considered a variation of *autistic spectrum disorder (ASD)* or *pervasive developmental disorder not otherwise specified (PDD-NOS)*. Autism is referred to as a spectrum disorder characterized by a delay or abnormality in at least one of the following areas: “. . . social interaction, communication or patterns of restricted, repetitive, stereotyped interests and activities” (Kluth, 2003, p. 5).

While the above deficits are apparent in diagnosing and qualifying Asperger's syndrome, it is important to also note how someone with Asperger's syndrome understands and describes his or her own strengths and challenges. Gillingham (2000) points out the limitations and often confusing criteria used to diagnose or differentiate between Asperger's syndrome and autism. She notes that most definitions of autistic

spectrum disorders do not come from direct experience. Gillingham contrasts and compares the qualitative descriptions of depression versus the outsider's view of autism:

When we look at the criteria for depression, we find it includes symptoms such as recurrent thoughts of death, markedly diminished interest or pleasure in all activities and feelings of worthlessness. None of these symptoms can be determined without taking the actual experience of the person diagnosed with it into account . . . This does not happen with autism, Asperger's syndrome or PDD-NOS. There is no mention at all of the actual experience of autism in the DSM-IV. (2000, p. 196)

The above quote underscores the need to understand the difference between the diagnostic and clinical understanding of Asperger's syndrome and the actual experience of having or being a person diagnosed with the disorder. Asperger's syndrome is often described as a mild form of autism or high functioning autism. Jackson (2002), a person diagnosed with Asperger's syndrome, defines the label this way:

AS is usually described as a mild form of autism but, believe me, though the good outweighs the bad, there are some bits that most certainly are not mild. AS people reading this: Do you feel as if you only have a "mild" problem when you are having one of those days where you feel as if you may well be from another planet? (p. 21)

Molton, a woman with Asperger's syndrome, stated:

No matter how high functioning we are, a great deal of effort is going into coping. Some people have called Asperger's syndrome "nerd disorder" as a way of minimizing it. There is a fine line between "normal but odd" and "very high functioning autistic." My personal opinion is that the line is where the traits become disabling. I have a very good "guest mode" where I can appear quite normal; however, being forced to sustain guest mode for an extended period can and has led to a serious breakdown. My ability to behave near normally at times has led others to believe that I can do it all the time and if I don't that I am lazy, unmotivated, manipulative, and deliberately annoying. No one expects a tightrope walker to do it all the time. (As cited in Kluth, 2003, p. 7)

Many adults with Asperger's have often stated they feel like an alien trying to learn the rituals and customs adhered to by humans who inhabit the earth. Page (2007), an adult with Asperger's syndrome, wrote about this in a personal experience article in a

popular mainstream magazine. Page stated, "Learning to make genuine connections with people, much as I desperately wanted them, was a bewildering process. I felt like an alien, always about to be exposed . . ." He went on to describe his tendency to get caught up in the details and miss the big picture in almost all aspects of life: "Not only did I not see the forest through the trees; I was so intensely distracted that I missed the trees for the species of lichen on their bark" (p. 38).

Dubin (2005), also diagnosed with Asperger's syndrome, describes how oftentimes his disability has been unnoticed or hidden, but has presented major barriers to functioning:

We may not even seem odd behaviorally upon an initial meeting, which is why Asperger's is often called the "hidden disability." More accurately stated, the hidden barriers to social communication are often present. The barriers I am referring to are invisible and intangible but nevertheless present. They are the "soft signs" that make having Asperger's syndrome so difficult. Whereas with classic autism the barriers are visible and obvious, with Asperger's, it is more subtle. As a result, other people may wonder why there seems to be a hidden disconnect between themselves and the individual with Asperger's. (p. 5)

As Dubin and the other individuals diagnosed with AS point out, while they may look normal to outsiders, their struggle to relate can be overwhelmingly difficult and near impossible at times. Even though AS has often been viewed as a mild form of autism, the adults who have been diagnosed with this disorder describe significant, disabling road blocks when it comes to social interactions and establishing relationships.

Though the genesis of Asperger's syndrome is relatively recent, over the last 10 years there has been a steady increase in the numbers of children being diagnosed with autistic spectrum disorders. Cathcart (2007) cited Reinberg's February, 2007 report regarding the latest statistics from the Center for Disease Control and Prevention (CDC) ". . . 1 out of every 150 American children born today will fall somewhere on the autistic

spectrum.” (para. 9-12). This rapid increase has brought a great deal of skepticism from the psychological community. Questions of misdiagnosis or over diagnosing are frequently raised. There is much about autism that is not understood, including its causes and the highly controversial concept that it can or should be cured.

Understanding the origins of Asperger's syndrome and the characteristics associated with the disorder is important; yet it would be a grave mistake to believe that any two people with AS are the same. Understanding what motivates and drives each individual can be a helpful way to engage, teach, and relate to someone with Asperger's syndrome, versus focusing on the deficits or pathology.

For the purposes of this study, the primary researcher defines adult AS as an individual who struggles with social interaction, the ability to understand and respond appropriately to nonverbal communication, possesses motor planning challenges, and demonstrates an overarching interest and extreme expertise in particular subject areas. These subject areas are selected because they provide a haven from social awkwardness and discomfort. They are often characterized by their predictability, reliability, and lack of interpersonal demands.

Special Interest

One of the primary characteristics in a person diagnosed with AS is the inclination to develop an area of *special interest*. The special interest often takes on a proportion that surpasses the commonly understood concept of a hobby.

The person with AS spends enormous amounts of time gathering information, researching, and discussing his or her unique and sometimes esoteric special interest. Attwood (1998) states that people diagnosed with Asperger's syndrome have “. . . a

special interest such as transport, animals, or science. These interests come and go, but dominate the child's free time and conversation" (p. 14). Attwood goes on to discuss the fact that often a person diagnosed with AS has "... remarkable long-term memory, exceptional concentration when engaged in their special interest and an original method of problem solving" (p. 9). According to Attwood (1998), any topics or tasks that fall outside the area of interest are met with "... a lack of motivation and attention" (p. 9).

Frith (1991) writes about the special interests of children with autism:

Another autistic boy was obsessed with poisons. He had a most unusual knowledge of this area and possessed a large collection of poisons some quite naively concocted by himself. He came to us because he had stolen a substantial quantity of cyanide from the locked chemistry store at his school. Another was preoccupied by numbers. Complex calculations were naturally easy for him without being taught. The same child who astounded others by solving complex math problems had the most serious learning disabilities at school, and could not learn the simple calculation methods that were taught. (p. 72)

It is evident that Frith (1991) quickly assessed the incongruence that exists in the person with AS. On one hand, these children display much talent with regard to their special interests; however, they are at a loss when applying the interests in conventional settings.

Gillberg (2002) explains and differentiates between a hobby or interest and an obsessive pursuit that exists with people diagnosed with Asperger's syndrome. "The special interest is usually isolated and does not inspire interest in others" (p. 33). Gillberg gives the example of a 10-year-old boy with a special interest in the French queen Marie Antoinette; obviously he was not popular among his peers. Oftentimes these interests can be regarded as "... absurd, weird or crazy" (pp. 33).

The Aspergerian special interest is therefore different from a simple hobby in that the nature and intensity with which the person pursues the information usually creates

severe isolation. Oftentimes the obtuse interest is not a common contemporary topic with peers. Social naiveté can be another aspect of AS. This can be often seen when the person with AS tries to use his or her unique special interest to reach out to others and becomes an object of ridicule.

Gillberg (2002) writes about the complexity and the often negative aspects attached to having narrow special interests:

Sometimes there are two or three special interests at the same time, but rarely more than that. The interests may come and go, even though a proportion will stick with their first “and only” interest throughout life. Even when interests change, the style in which they are adhered to rarely does. Again, it has to be said that it is not the interest itself, but rather the character of the person's relationship to the interest that is the problem. The individual with Asperger's syndrome so engrosses himself in the interest that it becomes tedious, indeed painfully so, for other people. (pp. 33-34)

Dubin (2005) discusses his special interests and how they did not coincide with the interests of his peers. He describes his indifference to popular culture as something that made him stand out from an early age:

As a kid I knew I was different. Those differences seemed to surface more in adolescence but they were always there. My interests, for starters, were unusual, even as a third grader. Besides the intense interest in game shows, I knew everything about expressways and highways. I knew that interstate 90's Eastern terminus was Boston and the Western terminus was Seattle. As a matter of fact I could tell you the starting and ending points of any interstate highway in the country. I could even include major cities that each one passed through . . . But it wasn't just my interests that alerted me to being different. It was also my way of being, my taste in music, my indifference to popular culture and my lack of social ability. (p. 8)

Attwood (1998) describes a developmental sequence for the person with AS in his research. The first stage begins with an intense interest in collecting items at every possible opportunity. Attwood states:

The child appears to have a visual acuity that identifies each specimen from a distance and cannot be distracted or persuaded to abandon an opportunity to

collect just one more. Eventually the child decides to change to a new type of object, but this continues to be a solitary pursuit and often independent of the latest craze of his peers. (p. 90)

According to Attwood (1998), the second stage is a fascination with a topic rather than an object. Common topics he cited are modes of transportation, dinosaurs, and electronics. In the second developmental stage of the special interest, the individual with AS begins to gain an encyclopedic knowledge about his or her topic. Attwood asserts that the interest begins to take on an obsessive quality that includes incessant questioning and reading any information remotely related to the topic. This includes memorizing owners' manuals and reports on any type of statistic that would broaden their knowledge on the subject. Attwood provides an example of a man with an interest in trucks:

As he walked home from work, he would remember each truck he saw and assign the vehicle points based on its rarity. A Volvo truck was relatively common and would only achieve one point for its manufacturer, while a Mercedes truck was rare and would achieve five points. When he arrived home, he would distribute the points to adjust his unique league table of truck manufacturers. (p. 90)

Attwood (1998) characterizes the third stage in the development of special interests as a romantic, rather than intellectual awareness toward a person, versus a topic. Attwood states: "The individual who is the focus for adulation may be mystified as to their intentions and parents are concerned about how this may be misinterpreted" (p. 91). The AS individual usually experiences this intense adulation in late adolescence or early adulthood.

For the purpose of this study, the primary researcher defines special interest as incorporating the above concepts and includes a highly focalized fixation that often takes on an obsessive-like quality. Further, from the literature, special interests can also be

termed as restrictive, repetitive or circumscribed interests, often referred to as passions or obsessions.

Adult

Corsini (1999) defines adult as “. . . a person old enough to engage in certain activities or to undertake specific obligations” (p. 22). According to Salkind (2004), the young adult is “. . . well on the way to a successful career and intimate personal relationships” (p. 151). Erikson (1950) believed the primary issues or life themes of adulthood include intimacy versus isolation, generativity versus stagnation and ego integrity versus despair. Berk (2007) states that people in their early twenties feel a sense of control in their lives and fear losing their freedom, while later adulthood is characterized by the development of family units and the mastering of skills needed to succeed in a chosen career. In the *Longman Dictionary of Psychology*, Goldenson (1984) describes the adult ego as “. . . the component of the personality that represents a mature capacity to deal with current reality” (p. 19). Kazdin (2000) states that the primary theorists on adulthood and ageing describe adulthood as a time where a person begins to “. . . make commitments to social roles builds on resources of personality developed earlier in life. In turn, personality develops in roles and contributes to further personality growth, which leads to happiness and well-being in later life” (p. 81). All the above authors and theorists identify three primary shifts that take place from adolescence to adulthood, including a greater focus on relationships, employment, and financial independence. For the purpose of this study, adulthood will include people no younger than 18 years old.

Experience

Goldenson (1984) describes experience as “. . . an event that is lived through, or undergone, as opposed to one that is imagined or thought about; the present contents of consciousness: also, knowledge or skill resulting from practice or learning” (p. 275).

The *American Heritage Dictionary* (Houghton Mifflin, 1982) defines experience as “. . . an event or series of events participated in or lived through personally” (p. 462).

While the above two definitions refer to a one-dimensional aspect of experience, to simply understand it in these terms would decrease the richness and complexity that encompasses the depth of the word experience. Gendlin, as cited in Klein (2001), states:

We can no longer construe “experience” so narrowly. Besides logical schemes and sense perception we have to come to recognize that there is also a powerful felt dimension that is prelogical, and that functions importantly in what we think, what we perceive and how we behave. (p. 1)

Gendlin brings to the surface three primary aspects rooted in the concept of experience, including logical schemes, sense perception, and felt dimension.

Logical schemes is the first dimension and refers to understanding or organizing an experience through the process of reasoning. For the purpose of this study, the adult with Asperger's syndrome is describing their special interest within a logical and orderly framework. This includes an attempt to express and articulate his or her cognitive and surface understanding of the special interests.

Wortman, Loftus, and Marshall, as cited in Klein (2001), define sense perception, the second dimension, as:

. . . the process whereby stimulation or receptor cells in various parts of the body (the eyes, ears, nose, mouth, and surface of the skin) sends nerve impulses to the brain, where these impulses register as a touch, a sound, a taste, a splash or color and so forth. Perception in contrast, is the process whereby the brain interprets the sensations it receives giving them order and meaning. (p. 85)

In this unique definition, the authors view sense perception as two separate functions. However, for the purpose of this study, and because it is arguably quite challenging, if not impossible, to differentiate between sensing and perceiving, this dimension will be defined as one function, termed *sensory awareness*. Therefore, the research participants will be asked to consider and address anything they are or were conscious of from a sensory perspective when engaging in thinking about their special interest.

The third dimension of experience is identified as the felt dimension or prelogical. This refers to a person's intuitive or natural ability, which often occurs outside a person's own awareness and may not contain a rational or logical component. This may be a difficult aspect for the co-researchers to address. Because people with Asperger's syndrome tend to be highly logical and concrete, dealing with aspects of experience that exist outside the concrete understanding of their special interest may not emerge. However, it is an important aspect for me to address and attempt to understand.

Social Relevance

Over the last 10 years there has been a great deal of research done on Asperger's syndrome. However, much of the research focuses on the pathology or obsessive characteristic of the special interests of a person diagnosed with AS. The goal of this research is to help professionals, parents, and educators understand the function and nature of the special interest in order to maximize and utilize the interest as an adaptive skill versus a liability. To truly understand the experience of having a circumscribed interest, one must look through the eyes of the person diagnosed with Asperger's

syndrome. The interest can be seen as either a barrier or a social, educational, or therapeutic opportunity.

Attwood (2003) hypothesizes that special interests serve various purposes such as decreasing anxiety, increasing relaxation and pleasure, ensuring predictability, creating meaning in the physical world, escaping from the current reality, building identity, elevating social status by becoming an expert, and occupying time. However, all of these theories will simply remain speculation until more qualitative research is done from the point of view of the Asperger's syndrome population. If there is truth in the above ideas it would be beneficial to deepen the clinical knowledge and understanding of special interests.

Based on the readings completed by the primary researcher, it was found that behavioral therapists create treatment plans with the goal of extinguishing the special interests that are regarded as an addiction. All access may be denied to the individual's special interest or access is given only as a reward. Is this the best way to handle special interests? Is managing the special interest a productive therapeutic goal? Attwood (2003) states, "The interest can either be a bridge or a barrier to social contact" (p. 191). He goes on to explain that special interests can also be used constructively in therapy or at school: "When one considers the attributes associated with special interests, it is important to consider not only the benefits to the person with Asperger's syndrome, but also the benefits to society" (p. 199).

While there may be aspects of the unique interests that need to be managed, it seems important to those who work and live with individuals with AS to understand more about the nature and function of the special gifts and limitations that dwell within them.

Summary

In this chapter, the personal relevance and the professional connections to this area of research have been explored, the research question has been stated, and the terms that comprise the topic have been defined. Lastly, the social relevance of the research has been discussed. In the next chapter, the relevant literature existing on the topic of adults with Asperger's syndrome and their relationship to their special interests will be reviewed.

CHAPTER II

Literature Review

This chapter examines the scope of relevant literature on adults with Asperger's syndrome and their special interests. The goal of the review was to provide a comprehensive and up-to-date historical accounting of available literature, uncover academic debates pertaining to the topic, demonstrate the researcher's knowledge in the area of autism, and position the study in the field of psychology as a unique contribution to the existing body of research on special interests and Asperger's syndrome.

The chapter is organized into seven primary categories: 1) the criteria for diagnosing Asperger's syndrome and how that relates to special interests; 2) an overview of research regarding the functional, developmental, and evolutionary aspects of special interests; 3) the neurology of special interests and savant syndrome; 4) the pathology of special interests; 5) voices from those with Asperger's about their special interests; 6) giftedness and special interests; and 7) a review of qualitative and quantitative studies that pertain to Asperger's syndrome.

Criteria for Diagnosing Asperger's Syndrome

Today, Asperger's syndrome is found under the umbrella of *Pervasive Developmental Disorders* (PDD) in *DSM-IV* (APA, 1994). Pervasive Developmental Disorders characterize all disorders involving impairments of social interactions, communication, and imagination. Currently, Asperger's syndrome is considered a variation of autistic spectrum disorder (Attwood, 1998).

Asperger's syndrome was first described by the Austrian physician Hans Asperger. Asperger (1944) cited a disorder that was labeled *autistic psychopathy*,

evidenced by impairments or oddities in the areas of social interaction, speech, and intense interests or fascinations. Krevlin (as cited in Ghaziuddin, Leininger, & Tsai, 1995) compares autistic individuals with those diagnosed with Asperger's syndrome. Individuals with AS are believed to have a better social prognoses, although they are often more clumsy and pedantic in their speech patterns.

Asperger's (1944) work was virtually unknown until a groundbreaking paper written by Wing (1981). Wing discussed a particular pattern of behavior outlined earlier by Asperger in 1944. Frith (1991) later translated Asperger's original paper into English.

Prior to Asperger's research, an account of six boys described with Asperger-like characteristics was published in a German journal by a Russian woman psychiatrist, Ssucharewa (as cited in Wing 2005) and was later translated into English by Wolff. Ssucharewa described the boys as having a schizoid personality disorder. Wing (2005) indicated that it was by chance that Asperger's name, rather than Ssucharewa's, became associated with the syndrome.

The literature revealed a great debate among clinicians with regard to diagnostic criteria pertaining to pervasive developmental disorders. The question at hand was whether autism and Asperger's syndrome should be considered the same disorder but on different ends of the spectrum, or separated and discussed as separate nosological entities. That debate had a direct impact on this research. Many of the articles included in this review considered AS and autism as one and the same. In this research study, high functioning autism is not delineated from Asperger's syndrome. According to Kerbashian, Burd, and Fisher (1990), the primary difference between AS and autism are

the circumscribed interest patterns. In the following discussion, the diagnostic criteria will be presented and examined.

Frith published a book on Asperger's syndrome in 1991. In her work she explored the commonalities and differences that exist between the diagnostic criteria in autism versus Asperger's syndrome. She laid out four basic features that characterize Asperger's syndrome: 1) clumsiness and poor motor coordination not always observed in people diagnosed with autism; 2) higher level of social functioning than those with autism, but peculiar and naïve patterns of engagement; 3) odd use of language in which expansive amounts of words are used to describe favorite subject areas, but often there is a lack of abstract comprehension, in contrast to autistic-like mutism; and 4) average to above average intelligence.

Treffert (n.d.) noted a Swedish study done in 1989 that suggested that AS may occur in as many as 26 out of 10,000 children. Based on this statistic, some theorists suggested a strong genetic component contributed to or caused the condition. Other clinicians purported that there may be subgroups within the Asperger's syndrome itself.

Treffert (n.d.) cited additional characteristics of AS: 1) speech not usually delayed and sometimes advanced; 2) similar to autistic individuals, speech patterns are repetitive and tone can be monotone or flat, accompanied by overall pronoun confusion; 3) poor eye contact, with bouts of staring through someone; 4) repetitive activities are preferred; 5) intense attachment to objects; 6) deep seated desire for sameness or a resistance to change in schedules; and 7) prodigious memory with a preoccupation or expert-like status in one or two subject areas (special interests) that possess a quantitative component such as bus schedules, sport statistics, calendars, and historical dates. These islands of

knowledge are not often used in socially reciprocal ways to forge human connection. Instead these dissertations or outpourings of knowledge on the special subject come from rote memory and were described as expansive and pedantic.

In a paper on Asperger's syndrome, Wing (1981) said that AS is characterized by impairments in social interaction, communication, imagination, and repetitive or circumscribed interests similar to the traits ascribed to autism. While many researchers believed that AS is a neurological disorder (Malloy & Vassil, 2002), there was a great deal of confusion around diagnostic boundaries and the fact that the clinical presentation of AS changes with age. Singer (as cited in Malloy & Vassil, 2002) noted there is little clinical consensus as to what to call this group of impairments, and often Asperger's syndrome is used interchangeably with high functioning autism.

There are four resources used to diagnose Asperger's syndrome, which included checklists created by both Gillberg and Szatmari. Both U. S. (*DSM-IV*) and international (*ICD-10*) diagnostic sources also provided criterion and categorical requirements to assess and determine the presence of Asperger's syndrome. The criteria differed regarding speech delays among children before three years of age. Both the *DSM-IV* (APA, 1994) and the *ICD-10* (WHO, 1992) required age appropriate language development to diagnose AS.

Gillberg (2002) outlined four definitions of Asperger's syndrome commonly found in the literature. The first operational diagnosis of AS was presented in 1988 by Gillberg and Gillberg at the First International Conference on Asperger's syndrome in London, England. The criterion was based on the descriptions provided by Hans Asperger's case studies. Gillberg (2002) identified the primary characteristics, which

included six categories: social impairment or extreme egocentricity, narrow interest patterns, compulsive need for routines, speech and language peculiarities, nonverbal communication problems, and motor clumsiness.

However, Szatmari (1989), in his diagnostic requirements for Asperger's syndrome, did not include the narrow interest patterns that Asperger and Gillberg required for their criteria. Szatmari (1992) highlighted four primary categories, including: social isolation, impaired social interaction, impaired non-verbal communication, and speech and language peculiarities. Szatmari's guidelines could only be considered if the individual did not meet the criteria for autistic disorder.

The *ICD-10* (WHO, 1992) stated that there could be no speech delays reported or present in the first three years of the child's life in order to be diagnosed with Asperger's syndrome. Further, the diagnosis of AS cannot be given if the child previously met the requirements of childhood autism. Only three out of eight criteria must be met for a diagnosis.

The *DSM-IV* referred to Asperger's syndrome for the first time in 1994. The *ICD-10* and the *DSM-IV* diagnostic requirements focused on the absence of a language delay. According to Klin, Pauls, Shultz and Volkmar (2005), the advent of the *DSM-IV* definition was intended to create a ". . . consensual diagnostic starting point for research but it has been consistently criticized as overly narrow, rendering the diagnostic assignment of AS improbable" (p. 221). The lack of consensus is problematic for parents and clinicians as well as for researchers.

Another confusing aspect is the varying diagnostic criteria between genders. Wing (1981) stated that there are 15 times as many males as females diagnosed with high

functioning autism or Asperger's syndrome. However, when Wing assessed individuals with learning difficulties in conjunction with autism, she found the ratio was closer to 2:1. This suggested that females are less likely to develop autism, but when they did they were more severely affected or impaired. This raised concern as to whether females with AS presented with a different set of traits or learning styles than their male counterparts.

Wilkinson (2008) presented a study that identified a gender gap between males and females. She asserted that girls are being under diagnosed or missed altogether by doctors, parents, and school administrators. Attwood (2003) revealed that boys are referred for diagnosis 10 times more frequently than girls. Faherty (2006) purported that because females are socialized differently than boys, the disorder manifests in atypical ways. If girls presented with a different set of symptoms, it is highly likely they would be overlooked. Gillberg and Coleman (2000) reported that females diagnosed with AS had fewer special interests, and better imitative, language, and social skills than boys identified with Asperger's syndrome. Ehlers and Gillberg (1993) hypothesized girls with AS were better at masking their social difficulties in group situations and looked less disruptive in the classroom. Bazelon (2007), in a major newspaper article that addressed gender differences in autism, interviewed Cathy Lord, director of the Autism and Communication Disorders Center at the University of Michigan. Lord believed that girls had the ability to develop friendships, but by middle school many of them were stricken by anxiety and depression along with being diagnosed with Asperger's syndrome.

There was little consensus in the field of psychology regarding the exact diagnostic criteria needed to accurately diagnose Asperger's syndrome and few studies have examined gender differences in the expression of autism (Wilkinson, 2008). Many,

but not all of the diagnostic classifications, included narrow interest patterns. The above discussion regarding Asperger's syndrome is relevant to this literature review in that it addressed the criteria regarding the definition of Asperger's syndrome and special interests. This in turn is related to the degree to which any kind of mental health services may be available to treat those with this diagnosis. Not only are special interests not present in everyone with AS but it is not a universally agreed upon criterion for an AS diagnosis, as this study reveals.

An Overview of Research Regarding the Functional, Developmental and Evolutionary Aspects of Special Interests

Attwood (2003) discussed circumscribed interests as an enduring and unique aspect of Asperger's syndrome. Bashe and Kirby (2001) stated, "Beyond the basic triad of social disabilities typical of all pervasive developmental disorders, AS has its own core of common symptoms" (p. 37). The primary symptom they referred to is ". . . their all consuming interest in one or more particular topics" (p. 37). In a survey of 100 parents, Bashe and Kirby (2001) reported that 100 percent of parents indicated their child with AS had one or more special interests. Attwood (2003) believed the interest can be a bridge or a hindrance to meaningful social interaction and gainful employment. He discussed the evolution of the special interest over time and the triggers that may spark a new interest. Attwood (1998) stated that one of the ". . . characteristics we have the least clinical knowledge and research data about is the presence of the circumscribed interest" (p. 127). The presence of circumscribed interests appeared to be a primary characteristic that occurred in more than 90% of children and adults with AS (Bashe & Kirby, 2001; Kerbeshian, Burd, & Fisher, 1990; Tantam, 1991). The special interest was also

documented as being a character trait that remains stable (Piven, Harper, Palmer & Arndt, 1996). Yet as Attwood (2003) explained, “We have yet to describe adequately the nature of the interests and how they change over time, or the consequences and function of the interests, or strategies to reduce or utilize them” (p. 127).

According to Bashe and Kirby (2001), special interests can emerge as early as the age of two. Attwood (2003) described special interests as a “. . . preoccupation with parts of objects, such as spinning the wheels of toy cars or manipulating electrical switches” (p. 128). The next stage is characterized by a fascination or fixation regarding a specific topic and can include the collecting of objects. Attwood (2003) stated these children’s “. . . near encyclopedic knowledge can be astonishing; they may be perceived as little professors, eager to read about their interest” (p. 129). Further, “Some children with AS convey the impression of being potential geniuses” (p.129). In the teenage years Attwood (2003) indicated the interests can evolve to include “. . . electronics, and computers, fantasy literature, science fiction, and sometimes a fascination with a particular person” (p. 130). Attwood (2003) conveyed that the “. . . joy of the special interest also includes the categorization and the accumulation of the information” (p. 131).

The acquisition of knowledge in the chosen interest is a solitary activity. Bashe and Kirby (2001) stated:

The number one way kids with AS pursue their special interest is by talking about it. In contrast, adults with AS are more likely to read about their special interest than to talk about it. A special interest exchange is noticeably a one-sided, run-on, and more a monologue than conversation. (p. 39)

Attwood (2003) also spoke to solitary states. He stated, “Whereas the young child may ask adults many questions, and the older child may read about his or her interest, both engage in solitary and intuitive problem-solving activity” (p. 131). Attwood (2003)

described how special interests can change or vary, based on the age and intellectual capacity. He stated, "Over time there is a progression to multiple and more abstract or complex interests, such as periods of history, specific countries or cultures" (p. 129). In discussions of the genesis of special interests, the literature noted individuals with AS often develop more than one interest at a time. Bashe and Kirby (2001) conducted a survey of 150 adults with Asperger's syndrome about their special interests. They found many adults with AS develop two or more simultaneous interests and 17% of adults within the 142 people sampled documented having six or more interests.

Using Pinker's (1997) principles of evolutionary psychology to frame their research, Baron-Cohen and Wheelwright (1999) hypothesized that special interests or obsessions would evolve into cluster areas that were object-focused rather than people focused. They established two primary challenges to human existence. First, an individual must understand and navigate the physical world; second, they must understand and interpret their social environment. Pinker divided these two categories into folk physics, or the basic knowledge of how the physical world of objects work, and folk psychology, which described the workings of the social world, and included concepts such as self awareness, motivation, and drive.

Previously, Baron-Cohen (1991) provided clinical evidence that people with autism experienced deficits in folk psychology. In Baron-Cohen's study, ninety-two parents returned the screening measure, which was designed to determine the subject of their child's interests. The questionnaire was sent to parents who were asked to check off their children's special interests from a list of potential obsessions. According to Baron-Cohen and Wheelwright (1999), the topics included in the questionnaire were machines,

systems, sorting or categorizing, belief systems, numerical information, sports or games, articles of an item, sensory experiences, crafts, factual information, creative arts and fiction, sciences, animals, collecting things, people, vehicles, spinning objects, food and drink, plans, and other.

The hypothesis of this study (Baron-Cohen & Wheelwright 1999) was that children with autism spectrum disorders and Asperger's syndrome would have interests that would cluster in the areas of folk physics rather than folk psychology. This proposed hypothesis was confirmed through the research study. An unexpected finding was that children diagnosed with autism were also found to have intense interests in television. The top five categories of interest for children with autism spectrum disorder included physics, taxonomy, television and audio, food, and sensory phenomena.

Additionally, the authors of this study discussed the validity of their results by comparing them with clinical accounts. Baron-Cohen and Wheelwright (1999) discussed the works of Bettelheim, who described a boy fascinated by machines, and the accounts of parents who described their children as being obsessed by electricity, pylons, and burglar alarms. While the literature cited these types of examples, that is, children and adults with AS possessing obsessions, there are few studies that qualitatively captured these accounts as described by those diagnosed with AS. Baron-Cohen and Wheelwright's (1999) study is closely related in some aspects to the current research; however, the information on special interests in the former study was obtained through parent reports and surveys, not the actual people diagnosed with AS, as in the current study.

In this study, the researcher interviewed adults with AS about their special interest experiences. The data collected represents first-hand accounts of the phenomena. This section began with a survey that validated the presence of special interests in children with AS. The validation of the presence of special interests served to reinforce the identification of AS. Special interests provided either a bridge to future success or an obstacle to it. For those with AS, the role and function of special interest varies. For some, it serves as a way to elevate social status and self esteem while for others it can essentially result in withdrawal and social isolation.

The Neurology of Special Interests and Savant Syndrome

In 2007, a progress report on brain research reviewed several studies on current findings in the area of autism (Hyman, 2007, para. 1-5). The following four major findings regarding brain abnormalities were discussed: 1) functional magnetic resonance imaging (fMRI) showed damage to the frontal gyrus or mirror neuron systems, which plays a crucial role in the ability to express and interpret emotions; 2) increased cortical thickness in the brain's temporal and parietal lobes, which may cause the enlarged head circumference in children with autism; 3) larger than normal amygdala, which is attributed to delays in language development and emotional regulation; and 4) transverse relaxation of brain cells (gray matter) or the brain's inability to displace water (para. 1-5). While these initial findings contributed to the overall understanding of the autistic brain, they did not explain the cause of autism or the development of special interests. Because special interest research is limited, the researcher sought out findings in the areas of other disorders closely related to autism where special interests or repetitive behaviors were noted as part of the overall presentation of symptoms.

Special or circumscribed interests have been linked to other psychological, neurological, and genetic dysfunctions including savant syndrome, Tourette syndrome, Williams Syndrome and Prader Willie. Lewis and Bodfish (1998) indicated that the emergence of these intense special interests was due to damage of the basal ganglia. The special interests could and often did evolve into what could be considered obsessive compulsive disorder (Baron-Cohen, 1989).

When special interests are viewed as part of neurological dysfunction evident in AS, the research revealed that special interests were discussed as repetitive behavior often described in the studies of autistic psychopathy. Repetitive behavior included self stimulatory behavior such as rocking, humming, or hand flapping. Lewis and Bodfish (1998) reviewed repetitive behavior in autism. One problem they identified in the literature was the lack of consensus among researchers with regard to defining repetitive behaviors. Lewis and Bodfish (1998) stated:

A given act such as hand flapping may be described as stereotypic, self-stimulatory, ritualistic, perseverative, gesturing, or posturing by different clinicians. Similarly, terms such as abnormal preoccupations, circumscribed interest patterns, abnormal object attachments, and idiosyncratic responses to sensory stimuli lack behavioral referents. (p. 80)

Lewis and Bodfish (1998) suggested, "Repetitive behaviors appeared to be related to alterations in dopamine, 5-HT, and opiate systems and their interactions in the basal ganglia" (p. 87). While there is some research in the neurobiological understanding of ritualized behaviors, Lewis and Bodfish indicated a need for "Comprehensive studies of the phenomenology of the full range of repetitive behaviors seen in autism" (p. 87).

According to Turner (1999), repetitive behavior can be subdivided into low and high-level behaviors. Low-level behaviors included repetition of movement such as

dykenesias, tics, self-injurious movements, and repetitive manipulations of objects such as lining items up in the same order. High-level behaviors included a desire for sameness, repetitive language, and circumscribed or special interests. Turner (1999) further stated that the highest level of repetitive behaviors in autism were the circumscribed interests, "These interests range from preoccupations with highly unusual aspects of the environment (such as the serial numbers of electrical appliances) to intense, all-absorbing interests in more common hobbies such as astronomy" (p. 840). Turner concluded that the literature in this area of autism ". . . reveals many questions that remain unanswered. At a basic level we still know very little about the natural history and development of repetitive behavior in general and higher-level repetitive behavior in particular" (p. 846).

Peek, possibly the most famous person connected to the world of autism, was characterized by Dustin Hoffman's role in a popular film, "Rain Man," in the '80s (Gruber & Levinson, 1988). Raymond, the lead character, was loosely based on Peek's life. This characterization served as a good example of a person with high-level behaviors. In the literature, Peek was termed a savant. Many people who could have been later diagnosed with Asperger's syndrome or high functioning autism were historically labeled as idiot savants. Treffert (n.d.) defined a savant as a person who had extraordinary capabilities in conjunction with a mental handicap. According to Treffert (n.d.) as many as 1 in 10 people diagnosed with autism have savant abilities. The primary difference between a savant and a person with AS is that a traumatic brain injury can cause a person to contract savant capabilities. In addition, many savants also have a desire to be social whereas a person with AS may not necessarily be inclined to interact with others.

Savant abilities are clustered into three primary categories: 1) splinter skills, described as an obsessive hobbyist, or a person who memorizes and amasses huge amounts of statistical information; 2) talented skills, described a person who has a particular talent in one area such as painting, drawing or composing, and possible abilities in solving complicated mathematic equations; and 3) prodigious skills, the rarest type of savant. Today there are less than 100 people in the world identified as prodigious savants. An example of this would be an individual who could memorize and play back an entire concerto after hearing it only once. Treffert (n.d.) differentiates between a savant and a prodigy: Savants, by definition, have their special skill or skills in spite of some basic mental disability, generally with low IQ scores overall, while prodigies are persons also with special skills or abilities without such mental disabilities who generally function at a normal or very high level overall and whose IQ scores generally reflect that function (p. 1).

Treffert (n.d.) described prodigious savants as having limitations or cognitive challenges that can be severe. What he believed makes them unusual is the ability to know things they were never taught. He characterized this innate ability or access to knowledge as genetic memory, or as Jung termed, the collective unconscious. This concept could be applied to many individuals with AS or high functioning autism who are diagnosed with hyperlexia, an ability to identify letters and numbers and read at an early age without having been taught.

Peek, according to Treffert (2005), is identified as a savant, and is noted to have 15 basic interests that include American history, sports, movies, geography, space programs, actors and actresses, the Bible, church history, space programs, literature,

Shakespeare, and classical music. Treffert (n.d.) also stated that currently, Peek has memorized all the area and zip codes in the United States. He learns the maps on the front of phone books and can give directions within any major city in America.

In contrast, Peek cannot button his shirt or pants, walks with an odd gait, has difficulty with abstraction, and does not possess the skills to live independently (Treffert, n.d.). According to Treffert and Christensen (2005), Peek's brain has many abnormalities, including an absence of the corpus collosum or nerve tissue that connects the right and left hemisphere of the brain. In addition, he was born with encephalocele (a baseball size blister on his brain), which resolved without surgical procedures. Some of these brain abnormalities explain Peek's motor challenges; however, his lack of a corpus callosum does not necessarily account for his functional disorders, (Treffert & Christensen, 2005, p. 295).

The doctors who have worked with Peek over the last 20 years speculated about how his brain has compensated to allow these latent talents for memorization to occur.

Treffert and Christensen (2005) stated:

Kim's brain shows abnormalities in the left hemisphere, a pattern found in many savants. What is more, left hemisphere damage has been evoked as an explanation of why males are much more likely than females to display not only savantism but dyslexia, stuttering, speech delay and autism. The proposed mechanism has two parts: male fetuses have higher level of circulating testosterone, which can be toxic to developing brain tissue; and the left hemisphere develops more slowly than the right and therefore remains more vulnerable for a longer period of time. What does this evidence imply? One possibility is that when the left hemisphere cannot function properly, the right hemisphere compensates by developing new skills, perhaps by recruiting brain tissue normally earmarked for other purposes. Another possibility is that the injury to the left hemisphere unveils skills that had been latent in the right hemisphere all along, a phenomenon some have called a release from "tyranny" of the dominant left hemisphere. (p. 110)

As we saw with Peek's exceptional abilities to memorize, his skills and challenges raised the following question about special interests or savant-like skills: "Does brain damage stimulate compensatory development in some other area of the brain, or does it allow otherwise latent abilities to emerge?" (Treffert & Christensen 2005, p. 110). Peek's IQ was tested in 1988; his full scale IQ was 87, which put him in the cognitively impaired range. According to Treffert and Christensen, Peek's overall diagnosis was *Developmental Disorder Not Otherwise Specified*. Treffert and Christensen agreed that one thing that does seem necessary for the full development of savant skills is a strong interest in a specific subject matter. It is important to note that while Peek was not diagnosed on the autistic spectrum in 1988, his diagnosis would probably be refuted based on current *DSM* criteria for the diagnosis of AS developed in 1994.

The primary researcher does not attempt to speculate on brain functioning, nor is it a discussion on the differences between savant syndrome, AS and high functioning autism. The intention of this research was to understand and explicate the nature and meaning of special interests to the person diagnosed with Asperger's syndrome. Special interests are often considered to be pathological manifestation of brain dysfunction, (Attwood, 2003). The preceding discussion of neurology and special interests highlighted the primary findings in that area of research.

Pathology of Special Interests

The special interests of a person with AS can demonstrate aspects of great intelligence. These attributes could be accompanied by serious issues that pose various problems, not only for the person with Asperger's, but for their families as well. Attwood

(2003) addressed the difficulties that can arise for the person with AS in relationship to their special interests:

Unfortunately, the determination to maintain access to the special interest can lead to problems within the family and society. For example: one child whose passion was trains took journeys without considering how to return and without informing his parents of his trip and destination. (p. 132)

According to Baron-Cohen (1989), the intensity of the interest took on the qualities of an obsessive-compulsive disorder, where the individual could not resist the desire to partake in their fascination with a particular subject. Attwood (2003) stated that people with AS who are otherwise law-abiding citizens can be tempted to break the law, utilizing “criminal offenses to obtain money to achieve access to circumscribed interests occurs” (p. 133). Joliffe (as cited in Attwood, 1998) described his obsessive interests in collecting candy:

I also liked collecting the lids of tubes of Smarties. These were orange, green, blue, red and yellow and had a letter of the alphabet on them. I had more orange ones and only a few blue ones and I never got all the letters of the alphabet. The only problem was that I wanted to take the lids off of all the tubes of Smarties when I was in a sweet shop so that I could see what the letter was underneath and this seemed to make other people angry. (p. 89)

In the above example, the child destroyed store merchandise in blind pursuit of his special interest, collecting tubes of candy.

Baron-Cohen and Wheelwright (1999) attempted to differentiate the origins of obsessive compulsive disorder and special interests:

A patient with OCD may have checking obsessions (e.g. a need to check the gas taps repeatedly) or washing obsessions (an excessive need to get rid germs on their hands and clothes). Hence when the patient with OCD has obsessions that typically involve fear of danger and harm and unwanted thoughts that are ego-dystonic and intrusive the patient tries to get rid of them though performing compulsions (Rachman & Hodgson, 1980), people with autism spectrum conditions typically follow their interests or hobbies to an extreme and narrow

degree, so that they become experts in a chosen field (Wing, 1988). In sum, the executive dysfunction theory ignores the content of the obsession. (p. 487)

The above quotation helps to delineate the special interest from an obsessive compulsion. In conjunction with obsessive compulsive characteristics, individuals with AS can also be seen as possessing delusional disorders. Attwood (2003) described a person whose special interest was superheroes and acted as if he was a superhero, "In an attempt to be successful and respected in social situations with peers, an interest in the supernatural during adolescence may be considered as indicative of schizophrenia" (p. 133).

Restricted, repetitive, circumscribed interests were viewed through the lens of pathology in the above literature. Links were made between restricted interests and damage to the basal ganglia (Lewis and Bodfish, 1998), along with associated disorders such as obsessive compulsiveness and delusions (Attwood, 2003). However, examples existed where special interests have been seen as strengths in an individual. The ability to hyperfocus on a particular topic had advantages. The discussion of special interests and its relationship to pathology is ever present in the literature and has a significant relationship to obsessive compulsive disorder according to Lynn, (2007). He indicated that at least 50% of people diagnosed with AS are reported to also have a moderate impairment from obsessions and compulsions. He does, however, delineate between obsessional thinking and special interests. He indicated that with classic OCD thinking, the individual will fixate on the idea that something terrible will happen if they do not wash their hands or touch the floor ten times. Whereas, "The AS child's involvement with the special interest usually calms and focuses him and does not cause him to become agitated or hyperactive" (Lynn, 2007, p. 117). According to Baxter (1992), certain brain

based differences distinguish OCD from engaging in special interests. Baxter suggested that the special interests are a fixed activity that cannot be captured on a brain scan as irregular neurological activity. Obsessive-compulsive activity, however, can be viewed on a brain scan and appears as overactivity of the anterior or cingulate gyrus, (Baxter, 1992).

The primary investigator's study does not intend to speculate or delineate the differences between AS and other neurological disorders. However, the review of literature provides an overview of pathologies that overlap with AS as they specifically pertain to the area of special interests. Therefore, the primary researcher's interest includes understanding more fully the relationship between the various pathological elements that may be present in this study. Clearly there is a commonality that links AS and OCD, although according to Baxter (1992), there is a difference in brain activity between the two diagnostic categories. While viewing AS in the context of pathology, those diagnosed with Asperger's syndrome see their special interests as a way to compensate and overcome their challenges.

Voices From Those with Asperger's About Their Special Interests

Jackson (2002), a boy diagnosed with AS, wrote about his special interests and how they impacted his life. He stated: "If one subject is on my mind or I am fascinated by something, then literally everything else is insignificant" (p. 43). Jackson recognized that his total absorption in one topic could cause him problems as others may view him as self absorbed or selfish. He described that when he became interested in a particular topic he felt an overwhelming need to "have to talk about it" (p. 44). Jackson (2002) used the word "obsession" to characterize his special interest in computers. According to Jackson,

“. . . most of the time my mind is so full of computers that I don't stop to think about myself or others at all" (p. 45). Jackson (2002) indicated that it is as if his mind is hijacked by the special interest. He stated: "One minute I am just very interested in a topic and the next it seems as if my mind has been infiltrated by an army . . . which eradicate my everyday thoughts and replaces them with thoughts of computers" (p. 44). Jackson (2002) recognized that using the word "obsession" when referring to special interests connotes a "negative or bad" association. He prefers the terms "favorite topic or subject" (p. 45). He believed that "A fascination, if channeled in the right way can be put to good use" (p. 45).

Tammet (2006) is an adult diagnosed with savant and Asperger's syndrome. His fascination or obsession with numbers is clearly evident in his memoir (2006) . In this except, Tammet describes his need to weigh out his porridge and count the number of clothing items he will wear before he leaves his house. He stated: "I eat exactly 45 grams of porridge for breakfast each morning . . . Then I count the number of items of clothing I am wearing before I leave the house" (p. 2). On the one hand, this OCD type of behavior can be seen as pathology. However, Tammet indicated that it provided a sense of calming and an ability to adapt and cope in the world. He also described a mounting sense of anxiety if he could not drink his cup of tea at the same time everyday. He wrote that whenever he became overly stressed and could not breathe, he closes his eyes and counts, "Thinking of numbers helps me to become calm again" (p. 2). Tammet (2006) stated that numbers are his "first language" and it is in this language he "thinks and feels" (p. 7). Tammet admitted to having difficulty with understanding emotions or how to react in certain situations. He uses his interest in numbers to help him with social scenarios and

provided this example. If Tammet had a friend who was feeling sad, he imagined “sitting in the dark hollowness of number 6” (p. 7). This helped him to experience the emotion of sadness and therefore he attained a sense of empathy towards his melancholy friend. He stated: “numbers actually help me get closer to understanding people” (p. 7). Tammet, like Jackson, believed that special interests have positive attributes and when channeled appropriately, can be put to good use and possibly act as a bridge to social understanding and connections.

Sacks (1995) is a psychiatrist who has written a great deal about people who suffer from neurological disorders. Sacks (1995) posits the theory that defects and disorders “play a paradoxical role, by bringing out latent powers, developments, evolutions, forms of life, that may never have been seen” (p. xvi). Sacks (1995) reveals seven case studies of people, some of which were diagnosed with autism or Asperger's syndrome. In each of the cases, he carefully highlights the paradox of ability that exists within the disability. Sacks hypothesized that if one particular brain pathway is destroyed “it forces the nervous system into making other paths and ways” which in turn “force on it [the brain] an unexpected growth or evolution” (p. xvi). Sacks interviewed Temple Grandin, a woman diagnosed with Asperger's syndrome, for one of his case studies, describing her in detail. He stated: “She spoke well and clearly, but with certain unstoppable impetus and fixity” (p. 257). He noted that “A sentence, once started had to be completed; nothing was left implicit” (p. 257). Grandin's special interest in animals has been successfully channeled into a career. She earned her doctorate in psychology and designs humane livestock chutes for animals. She currently consults with slaughterhouse companies about improving the effectiveness of their chutes, she teaches at the

university level, writes books, and speaks about autism and Asperger's syndrome. Grandin described herself to Sacks: "Almost all my social contacts are with livestock people or people interested in autism" (p. 261). She indicated that most weekends she spends working on writing books about autism or animals. She noted that she has "little interest in interpersonal relationships" (p. 261), but that her life has meaning because of her work advocating for the humane treatment of individuals with autism and animals. Sacks (1995) captured the notion iterated by both Tammet and Jackson: that is, special interests can be channeled and provide the individual with AS a bridge to social connection and meaningful career opportunities.

Lewis (2008) has written about her son Rex, who was diagnosed with autism and Savant syndrome. In her memoir, she described the experience of parenting a child who is both gifted and impaired. Rex, a musical savant, is also blind. He has difficulty with social reciprocity and speech. He is cognitively impaired and has both fine and gross motor challenges. He is sensitive to certain food textures, which make him an extremely picky eater, and is highly sensitive to certain sounds that can agitate him and cause temper tantrums, (Lewis, 2008). However, when Rex plays the piano, it is as if he is transported from a world of disability to profound ability or greatness. His mother stated that for Rex, "playing the keyboard was an override to dysfunction" (p. 43). Lewis (2008) wondered how Rex could overcome his fine and gross motor difficulties at the piano but could not snap his pants. She questioned "What was it in music that created such spatial order out of chaos in his brain and changed weak and fumbling fingers into vibrant strength?" (p. 138). Lewis (2008) hypothesized that her son's brain worked differently when playing the piano. Rex's musical abilities helped him excel in a particular area and

she believed that a part of his brain was not damaged. Lewis believed that as his mother, she needed to find a way to utilize his strengths to address the multitude of challenges he faced.

Giftedness and Special Interests

There is a great deal of literature about gifted children that sounded strikingly similar to the characterization of those diagnosed with AS. Webb, Amend, Webb, Goerss, Beljan, and Olenchak (2005) quoted a mother who described her gifted child. The mother stated, "My child's life motto is that anything worth doing is worth doing to excess" (p. 10). Webb portrayed these children as intense and possessing an excessive personality. These qualities depicted the passion and dedication a gifted child inherently had when it came to gaining knowledge about a particular topic of interest. Webb et al. (2005) also discussed the theory coined by Polish psychiatrist Dabrowski who portrayed gifted children and adults as having over-excitabilities. This concept was meant to describe the heightened sensitivities and high mental abilities of a gifted person, but could also be attributed to individuals with AS. According to Webb, theorists and clinicians who researched and worked with the gifted noted an inborn sensitivity to sensory stimuli and heightened responses. Dabrowski listed five areas of overexcitability: intellectual, imaginal, emotional, psychomotor and sensual. These core theories attributed to the gifted population could easily describe the Asperger's syndrome population.

According to Ledgin (2002) and Paradiz (2002), many contributions to the arts and sciences have been made by gifted individuals with AS. Asperger (as cited in Attwood, 2003) stated:

It seems that for the success in science or art, a dash of autism is essential. For success, the necessary ingredient may be an ability to turn away from the

everyday world, from the simply practical, an ability to re-think a subject with originality so as to create in new untrodden ways, with all abilities canalized into the one specialty. (p. 133)

Giftedness, in the literature on AS, often appeared under the heading of hyperlexia, a highly developed ability to recognize letters and words at a very young age (Tirosh & Canby 1993). However, this unique ability is often accompanied by difficulty comprehending the information that is read. Attwood (1998) described young children with AS who have a talent or gift for mathematics:

An interesting characteristic is that the child with Asperger's syndrome may not conform to the traditional sequence of stages in acquiring scholastic abilities and may take some time to learn basic skills or acquire precocious or original abilities using an unconventional strategy. The child appears to have a different way of thinking and problem solving. (p. 120)

Oftentimes hyperlexia, or giftedness in specific areas, also is accompanied by learning disabilities. Dubin (2005) spoke to the idea of *twice exceptionality*, being gifted and impaired at the same time. Throughout his life he struggled to make sense of his intellectual talents and abilities to read, yet he was diagnosed early on as learning disabled due to his motor planning and comprehension challenges. His verbal scores on intelligence tests were in the gifted range, yet his ability to sequence and his visual spatial processing were below average. Dubin (2005) reflected upon the incomprehensibility that he could be both gifted and impaired simultaneously. On the one hand, Dubin had tremendous challenges with fine motor coordination. He had terrible handwriting according to his teachers, and could not tie his shoes until he was in high school. Yet, in his early teens he became number one, or highest ranked player on his varsity tennis team. Both disability and exceptional ability present in one individual was difficult for

Dubin to grasp, and even more incomprehensible for his parents, teachers, and coaches to understand.

Gillberg (2002) speculated on the gifted quality of people with AS:

The possibility that prominent individuals who have forever put their mark on history in their respective field might have had the condition described by Hans Asperger, is hopeful for all of those whose lives are touched by Asperger's syndrome. Maybe one could even speculate that historic progress has quite often been made by people with autism spectrum conditions. The perseverance, drive for perfection, good concrete intelligence, ability to disregard social conventions, and to not worry too much about other people's opinions or critiques could be seen as advantageous, maybe even a prerequisite for certain forms of new thinking and creativity. (p. 134)

While certain people with AS might also possess attributes typically used to describe someone identified as gifted, most of the AS population also have areas of disability that sets them apart and often sets them back (Attwood, 1998).

Review of Qualitative and Quantitative Studies that Pertain to AS

The following studies shared a thread of commonality with the current research study. There were a number of dissertations that included case histories of individuals diagnosed with Asperger's syndrome; for example, Barrows (1988) used in-depth clinical case studies and explored the relationship between early infantile autism and Asperger's syndrome. The findings of this research asserted that a deficit in intersensory integration disrupts the autistic child's ability to perceive objective reality and the feelings and behaviors of others. Moreover, Barrows drew parallels between high functioning autism and other disorders involved in intersensory integration such as sensory integration dysfunction.

Winter-Messier and Herr (in press) conducted a study on young adults with Asperger's syndrome regarding their special interests. Using a mixed model approach,

the researchers utilized both quantitative means (surveys filled out by parents), and qualitative measures (interviews conducted over the phone and in person with young adults with AS), to better understand the origin and development of special interest areas or (SIAs). Participants were identified through the extended school year (ESY) programs in the Seattle, Washington public schools. Letters were sent to potential parents of children identified as being diagnosed with Asperger's syndrome. Thirty participants were invited to join the study and 26 parents agreed to participate. The intention of the study was to better understand the impact of special interests on children and youth with Asperger's syndrome and their families. The SIAs were defined as "passions that capture the mind, heart, time and attention of individuals with Asperger's syndrome" (in press). The findings revealed that the special interest areas served to provide positive purpose for the children and young adults with AS. The SIAs were considered to be viewed by the participants as an integral part of the AS individual's identity and self-concept. The SIAs provided a way to acquire lucid focus, systematize their world, and approach their societal environment. Many similarities are present between Winter-Messier and Herr's (in press) study and the research in this dissertation. The topic of special interests was the primary subject of both studies. This dissertation utilized a qualitative model, with no quantitative measures utilized. The focus of Winter-Messier and Herr's study was on young adults, whereas this dissertation targeted adults 21 and over. Winter-Messier and Herr's research also included data gleaned from family members of the individuals with AS.

Graffam (2005) documented one family's experience of having a child with Asperger's syndrome. Graffam utilized a case study research model and employed

ethnographic data collecting techniques. The researcher actually lived with the research participants for a short period of time. Data collection included interactions with each family member, interviews, and access to journals and letters from others outside the family that could shed light on the child diagnosed with Asperger's syndrome. The study sought to understand how each member of the family constructed meaning and understanding of the disorder. Siblings were also included in the interview process in terms of their shared experiences and anecdotes. The findings in this qualitative study concluded that each member of the family construed meanings about the child with AS based on their individual developmental level, worldviews, and background, (Graffam, 2005).

Macari (2003) studied the neuro-cognitive functioning and repetitive behavior in children diagnosed with autistic spectrum disorder. While this was not a qualitative study, it did address repetitive behaviors in children with autism. Researchers utilized the Autism Behavior Scale (ABQ) and rated ritualistic behavior, invariant behavior, motor and object stereotype, obsessive interests, strong preferences, and sensitivity and atypical affect. The results suggested the prevalence of ritualized behavior depended upon the age and the severity of autism. Neurological findings associated both the dorsolateral prefrontal cortex and the ventromedial prefrontal cortex with different types of repetitive behavior.

In a qualitative study by Wady (1996), eight people who were personally or professionally involved with an individual diagnosed with Asperger's syndrome were interviewed. The purpose of the study was to gain insight into strategies of building social networks for the adolescent individuals with AS. The participants were asked to

describe the diagnosis and ways of supporting social interaction for the adolescents with AS. Verbatim quotes were gathered from the participants. Findings indicated that establishing a network of well-educated, caring individuals who served as mentors, social advocates, and interpreters assisted in facilitating social interactions for those diagnosed with AS.

Larsen (2004) utilized a phenomenological heuristic auto ethnographic narrative approach to study the effects of autism on a family. Her research was intended to uncover the essences inherent in her experience of having a child with autism. Larsen utilized her knowledge as a mother of an autistic child as the central data for her research. She stated, "I have constructed my own representation of my life, in response to those who have written before me" (p. 70). The autoethnographic aspect of this research was used for the purposes of ". . . understanding how a culture and environment impact those who have a family member with autism" (p. 10). The focus of the study centered on the parents' perspective and responses to having a child diagnosed with autism, with a particular emphasis on the mother-child interaction. The literature review of this study addressed how autism manifests through language, cognition, genetics, and the impact this has upon family functioning. The researcher's own interaction and interplay with the research participant, her son, yielded a deeper understanding of what it meant and how it felt to have a child with autism. Larsen (2004) calls for further studies to be completed in the service of what autistic children can do and accomplish versus always focusing on ". . . what they cannot do" (p. 70). In her dissertation, an emphasis on her son's special abilities was highlighted. Larsen's phenomenological auto ethnographic narrative investigation has similarities to the current research in that her research utilized a

phenomenological model and included some discussion on the special abilities of people diagnosed with autism. However, her focus was on the mother's experience of having a child with autism, whereas in this study the central themes were derived from interviews with adults diagnosed with Asperger's syndrome.

Smily and Meredith (2003) completed a quantitative study on adaptive functioning in children and adolescents with high functioning autism (HFA) and Asperger's syndrome. The study utilized the Vineland Adaptive Behavior Scales (VABS). Subjects included eighty-six children and adolescents with HFA and AS that were divided based on age and diagnosis, and compared to a control group of typically developing peers. The results of this study indicated that children with HFA and AS may fall behind their peers in social skills, organizational abilities, and developing relationships, therefore impacting overall adaptive capabilities (Smily & Meredith, 2003).

Marieke (2003) completed a pilot study of the quality of life of young adults with Asperger's syndrome using quantitative measures such as the World Health Organization Quality of Life Measure and Perceived Support Network Inventory. The findings of the study indicated that adults with AS had less positive experiences in dating, employment, and income, which impacted their overall quality of life.

While many people in the field agreed special interests were part of the experience of having Asperger's syndrome, very little has been investigated from the perspective of the individual diagnosed with AS. The current research explored the experiences of those who have special interests in their own words. The interviews revealed an understanding of how the special interest impacts the person with AS over his or her lifetime.

The goal of this research was to understand the essence of special interests through detailed descriptions garnered from in-depth interviews with co researchers diagnosed with Asperger's syndrome, and to provide insight into these individuals' possible motivations (or lack thereof) at home, school, and on the job. This perspective appears to be unprecedented as no other studies of this nature were found. To date, the only relevant literature about AS and special interests from the point of view of the individual with Asperger's came in the form of memoirs written by Tammet, Grandin, Dubin, Newport, Shore, Willey, and Robison. Tammet (2006), diagnosed with Asperger's and savant syndrome, attempted to explain and help others understand his experience of living with AS. His hope was to connect to others and dispel the mysteries surrounding autism:

My younger brother Steven has recently been diagnosed with the same form of high functioning autism as I have. At nineteen, he is going through a lot of challenges that I too faced while I was growing up, from problems with anxiety, loneliness to uncertainty about the future. When I was a child, doctors did not know about Asperger's syndrome and so for many years I grew up with no understanding of why I felt so different from my peers and the world around me. By writing my own experiences of growing up on the autistic spectrum, it is my hope that I can help other young people living with high functioning autism, like my brother Steven, to feel less isolated and to have confidence in the knowledge that it is possible to lead a happy and productive life. (p. 12)

This research offers a first look at special interests through the eyes of those diagnosed with AS. By providing a forum for those with AS to voice their own ideas and understanding about themselves, clinicians, professionals, parents, and others with AS may gain deeper insight into the origin and evolution of the special interest over the course of an AS individual's lifetime.

Summary

This chapter has selectively reviewed the professional literature related to the research question and positioned the study within that context. In the next chapter, the differences between quantitative and qualitative research will be described, followed by a comprehensive explanation of the Transcendental Phenomenological research model used in this study.

CHAPTER III

Research Model

In this chapter, the rationale for the selection of the qualitative research model is discussed. The history and genesis of the Transcendental-Phenomenological model is explained and a description of the model, steps, theories, and concepts will be identified and defined. The qualitative model of Transcendental Phenomenology will be used to explicate how an adult with Asperger's syndrome experiences having a *special interest*.

In selecting the appropriate model for this research, it was clear that attempting to utilize a quantitative model would have many limitations. Quantitative studies involve the use of standardized methods, data, and statistics extracted from an analysis that either proves or disproves a hypothesis. In this study, the phenomenon of *special interests* is explored through the perspective of one diagnosed with Asperger's syndrome.

According to Patton (1990), qualitative research does not bear the burden of proving or disproving a theory "There is only the work to experience and understand. Shed the burden of proof to lighten the load for the journey of experience" (p. 7). The intent of qualitative methodology is to understand the depth and breadth of an experience. Patton (2002) asserts that qualitative research creates an opportunity for the researcher to gain greater insight into themselves and the phenomena being studied: "Qualitative inquiry cultivates the most useful of all human capacities--the capacity to learn from others" (p. 7).

Karlsson (1993) describes the nature of traditional research as explanatory while the intent of qualitative research describes the *what* and *how* of an experience by asking a question. Karlsson states, "If we wish to know what we explain we must engage

ourselves in the descriptive analysis of the phenomena in question” (p. 14). Patton (1990) cites a portion of Halcolm's Evaluation Laws that assert, “When in doubt, observe and ask questions. When certain, observe at length and ask many more questions” (p. 7). This concept illustrates the core intentionality of qualitative research. The focus is in the understanding and explication of an experience.

Polyani (1983) states “. . . we can know more than we can tell” (p. 4). This raises the question of how we understand something without comprehending the process we go through to be able to understand. A debate in psychological literature exists over the efficacy regarding qualitative research. According to Camic, Rhodes, & Yardley (2003), true knowledge can be gained only by the positive affirmation of theories utilizing quantitative data. On the other hand, based on the views of Camic et al. (2003), psychological research that adheres to the use of quantitative methods poses limitations due to an overreliance on what can be observed and quantified.

In the quantitative paradigm, the importance of the test and retest theory, absolute objectivity on the part of the researcher, and the ability to prove or disprove a theory is tantamount. Conversely, qualitative research allows the researcher to uncover the subjective by utilizing a naturalistic approach that seeks to understand an experience by collecting data from people who have actually experienced the phenomena. It is in the details of the descriptions that researchers illuminate their findings (Creswell, 1994). Qualitative research involves collecting descriptions of experiences and organizing and understanding the meanings assigned to those experiences. Karlsson (1993) differentiates between facts and meaning:

Facts are conceived of as objective and independent of consciousness, while meaning is considered subjective and idiosyncratic . . . phenomenology rejects the

idea that there exist objective facts independent of a subject or subjective consciousness. (p. 16)

Moustakas (1988) describes a growing discontent with the supposition that psychological research focus only on material things versus exploring the depth of human experience. He emphasizes the benefit of “. . . exploring the connections between human consciousness and the objects that exist in the material world” (p. 21).

Keen (1970) describes the logical unfolding and primary pitfalls with regard to the use of a quantitative model:

Individual observers may impose preconceived ideas and biases upon the observations, and in order to make sure this is not happening, many different observers must be able to repeat the operations and emerge with the same product and the same knowledge. The surest way to facilitate this procedure is to quantify. (p. 337)

However, Keen asserts, it is almost impossible to be totally unbiased in that “. . . we see what we intend, and we cannot see without intending” (p. 337).

While both quantitative and qualitative research models possess inherent strengths and weaknesses, it is helpful to understand the merits of both, and how, if utilized in conjunction, they could yield great benefits. Qualitative inquiries begin with a curiosity or questioning about a phenomenon. The researcher enters into the investigation to distill the essential experiences or essence inherent to the particular phenomenon. The findings from the qualitative inquiry can then be used as a foundation for postulating a theory. At that stage, the quantitative model can be employed to either support or disprove the supposition.

A qualitative model was selected for this study in order to gain a greater understanding of how an adult with Asperger's syndrome experiences his or her special interest. Much of the current and past research focuses on special interests clinically; that

is, an outside professional looking into the experience of others. In this study, the subjective experience of the adult with Asperger's syndrome will provide a unique understanding and perspective.

Once the decision was made to select a qualitative model, the researcher examined different methods potentially applicable to this realm of study. According to Creswell (1994), there are many options and research designs to choose from for the qualitative researcher. Moustakas (1994) indicates that grounded theory and phenomenology are well-matched methodologies for psychological researchers.

After considering other qualitative research models, this researcher was interested in a model that captured the research participants' experience. The intention of this research is to enter into the private world of adults with Asperger's syndrome to understand and explicate their experience of special interests. The qualitative model of Transcendental Phenomenology selected for this study aims to discover regularities, discern patterns, comprehend meaning, and allow for reflection on the process.

This research model was, in large measure, attributed to the work of Brentano (1838-1917), Husserl (1859-1938), and Heidegger (1889-1976) and applied by Moustakas (1994). Each of the above philosophers added unique insights and philosophical views that helped in developing the movement of phenomenology.

Van Manen (2002) notes that Husserl borrowed the concept of intentionality from Brentano in order to describe the structures of consciousness. Van Manen states, "All conscious awareness is intentional awarenesses . . . Transcendental phenomenology is therefore the phenomenology of consciousness" (p. 1). Brentano and Husserl are most

clearly identified with the work of Transcendental Phenomenology, while Heidegger is linked more closely with Existential and Linguistical Phenomenology.

Husserl, according to Keen (1970), viewed knowledge as “. . . the end product of a series of mental operations which had their beginnings in experience” (p. 342). Husserl attempted to create what he deems *descriptive psychology*, or a mode of research that included three basic components: 1) attending to phenomena; 2) identifying aspects of the phenomena essential to the experience; and 3) exploring the aspects that constitute the core essence or experiences gathered by the researcher (Keen, 1970). Moran (2000) describes the origins of the model:

Phenomenology was announced by Edmund Husserl 1900-1901 as a bold, radically new way of doing philosophy, an attempt to bring philosophy back from an abstract metaphysical speculation wrapped up in pseudo-problems, in order to come into contact with matters themselves, with concrete living experience (p. xiii)

This new philosophy was Husserl's attempt to transcend the limits of what is observed in consciousness and move to the explication of a deeper knowing or being in an experience.

The Phenomenological model addresses the micro and macrocosms of subjective human existence. According to Misiak & Sexton (1973), phenomenology examines “. . . whatever is found in consciousness or, in other words, the data or phenomena of consciousness” (p. 7).

Moran (2000) adds to the discussion on being presuppositionless, “. . . phenomenology's first step is to seek to avoid all misconstructions and impositions placed on experience in advance” (p. 4). The focus of this type of research is to capture the description versus an explanation of a particular phenomenon. Manen (1990) states:

The methodology of phenomenology is such that it posits an approach toward research that aims at being presuppositionless; in other words, this is a methodology that tries to ward off any tendency toward constructing a predetermined set of fixed procedures, techniques and concepts that would rule or govern the research project. (p. 29)

Moustakas (1988) summarizes his understanding of Transcendental

Phenomenology as a scientific study of the appearance of phenomena as they appear in consciousness. The primary challenge in doing this research is to “. . . explicate the phenomenon in terms of its constituents and possible meaning” (p. 28). Moustakas (1988) discusses Husserl's belief that phenomenological research is a “. . . science of experience” (p. 43). Furthermore, Moustakas (1988) adds that phenomenology is “. . . not as a science of facts but as a science of essential Being (as eidetic Science); a science which aims exclusively at establishing essences” (p. 44).

A researcher has two ways to gather data and gain access to these essences. According to Bogdan and Taylor (1984), the researcher can engage in participant observation where “. . . intense social interaction takes place between the primary investigator and the subjects,” or through data that is “. . . unobtrusively and systematically collected” (p. 5). The researcher can also gather data a second way, which includes the use of personal documents such as journals, pictures, letters, or open ended interviews where “. . . people reveal in their own words their view of their entire life, or part of it, or some other aspect about themselves” (p. 6). Either qualitative method can be utilized to ascertain the essential elements of experience.

Patton (2002) supports this elemental aspect of capturing experience and describes phenomenological research this way:

[Phenomenological research is] a focus on exploring how human beings make sense of their experience and transform the experience into consciousness both

individually and as shared meaning. This requires methodologically, carefully, and thoroughly capturing and describing how people experience some phenomena--how they perceive it, describe it, feel about it, judge it, remember it, make sense of it and talk about it with others. To gather such data, one must undertake in-depth interviews with people who have directly experienced the phenomenon of interest. (p. 104)

Steps of the Transcendental Phenomenological Model

Moustakas (1994) discusses the steps included in the Transcendental Phenomenological Model used to arrive at a deeper understanding of the experience being investigated. These phases include: 1) *Epoche*, in which the researcher clears his or her mind of presuppositions, judgments, or theories that would taint the findings of the study; 2) *Phenomenological Reduction*, which reduces the experience down to the core textural elements; 3) *Imaginative Variation*; which examines the structural aspects of the experience; and 4) *Synthesis*, which combines all the themes discovered into a descriptive narrative (Moustakas, 1994).

Epoche

The literal translation of *epoche* is to *stay away* or *abstain from*. Moustakas (1994) credits Husserl as the originator of the concept of *epoche*. Moustakas states, "Epoche requires the elimination of suppositions and the raising of knowledge about every possible doubt" (p. 26). Maslow (1966) describes the importance of *epoche* in a clinical sense:

Any clinician knows that in getting to know another person it is best to keep your brain out of the way, to look and listen totally, to be completely absorbed, receptive, passive, patient and waiting rather than eager, quick and impatient. It does not help to start measuring, questioning, calculating, categorizing, or classifying our theories. If your brain is too busy, you won't hear or see well. (p. 11)

The goal of the researcher must be to enter into the study and interview, free of preconceived notions, and to be open to the information collected. However, qualitative research accepts the premise that the researcher's emotions, history, perceptions, decisions and experiences will impact the study (Etherington, 2004). Epoche is to be used as a guard against this contamination process in conjunction with a certain amount of personal disclosure or transparency by the researcher. These disclosures create an awareness of presuppositions and outside influences the researcher may carry and project upon the data. Ruby (1980) describes the importance of including a reflexive aspect to an academic endeavor or study. He asserts that the researcher must demonstrate a willingness to be transparent and reveal the underlying assumptions that influenced the formation of the researcher's question. Once this task is addressed, epoche is engaged in by the researcher to clear away any remaining suppositions. While epoche is cited as the first phase in the transcendental phenomenological process, it is not a static or linear exercise. According to Craig (1978), Moustakas' components of the model allow the researcher to engage in a more dynamic and flexible fashion with the data. This is especially true for epoche, as it is utilized at every stage of this model. Yet Moustakas addresses the inherent difficulty in the process of epoche, despite its immense value:

My own experience in working with the epoche process is that I can set aside my biases. I can intend an open and fresh approach to my knowledge of something but the problem of language and habit still exist; my own rooted ways of perceiving and knowing still enter in. The value of the epoche principle is that it inspires one to examine biases and enhance one's openness even if a perfect state is not achieved. (pp. 60-61)

The goal of the researcher is to reach an unbiased stance. Ellenberger (1958) states, "In the presence of the phenomenon (whether it be an external object or a state of

mind), the phenomenologist uses an absolutely unbiased approach; he observes phenomena as they manifest themselves and only as they manifest themselves” (p. 96).

The intent of the researcher must be to clear away and abstain from any prior notions in order to be present and open to the experience and perceptions gained during the research participant's interviews and subsequent analysis. After the research question is posited, the researcher must seek out appropriate participants to interview for the purposes of collecting and interpreting data. The verbatim quotes taken from the interview process are transcribed and the text that emerges is utilized in the phases of phenomenological reduction.

Phenomenological Reduction

Phenomenological reduction is the second stage in the research model. Merriem (2002) depicts this stage as the “. . . process of continually returning to the essence of experience” (p. 94). Moustakas describes phenomenological reduction as the search to uncover the *what* of the experience, referred to as *noema*. Direct quotes are identified from the transcribed interviews that pertain specifically to the central issue explored in the study. Extraneous conversations within the text or topics discussed that do not serve to explicate the research question are deleted. Moustakas (1994) characterizes the noematic as the “. . . uncovering and explication, the unfolding and becoming distinct, the clearing of what actually is presented in consciousness” (p. 30). He goes on to illustrate this process as identifying “. . . descriptions of things just as they appear [reduced] to what is horizontal or thematic” (Moustakas, 1994, p. 91).

To understand this stage more clearly, consider the following example. Reflect upon the process of a sculptor creating a work of art from a block of marble. Without

having a preconceived notion of what will emerge, the artist will follow the grains, patterns and textures of the stone in front of him. Then, utilizing his tools, he will chip away at the nonessential stone in order to uncover the essence. If the artist remains open and unbiased, the material will reveal its truest form. So the phenomenological researcher pours through the text of the interviews, carves out what is nonessential in order to consider the elements that will serve to illuminate the experience. The remaining quotes function like the image emerging from the stone. As the marble's extraneous pieces are chipped away, the observer can begin to see what is being brought forth, or in phenomenological terms the noema, the what, becomes evident.

Moustakas states that for every noematic experience there is a noetic counterpoint that occurs. *Noesis* is the explication of the *how*. It seeks to uncover how beliefs about certain experiences are formed or acquired. It is the individual's train of thought as they come to understand how they know what they are experiencing. The noema (the what) is *what* we see, or our internal view of an experience. Whereas, the noesis (the how) refers to the *structure* of the experience. According to Moustakas (1994), the noesis is “. . . how beliefs about such objects (real or imaginary) may be acquired, how it is we are experiencing what we are experiencing” (p. 31). It is only through the integration of noema and noesis that the researcher can truly come to understand the full experience of the research participants.

Stages of the Transcendental Phenomenological Model

The methodology of the Transcendental-Phenomenological Model follows a systematic approach that includes five stages: *bracketing*, *delimiting*, *horizontalization*, *clustering and thematizing*, and creating *textural descriptions*. Moustakas (1988) states

that the phenomenological reduction process is vital for the researcher because he or she must engage in “. . . choosing what is core and eliminating what is fringe or tangential” (p.111).

Bracketing

The first step in the reduction process requires filtering. The intention of bracketing is to identify all the material that pertains to or correlates with the research question. Moustakas (1994) explains: “. . . bracketing, in which the focus of the research is placed in brackets, everything else is set aside so the research process is rooted solely on the topic and question” (p. 97). According to Holroyd (2001), the process of bracketing requires “. . . rigorous reflection of one's bias, opinions and cultural and socio-economic backgrounds” (p. 4). In order for the researcher to successfully engage in this process, he or she must consider his or her own bias and focus solely on the question central to the study.

Delimiting

In this stage, the researcher removes or delimits the bracketed information that is not relevant to the question. The researcher is then left with the main essences of the experience. Those statements or details that do not serve to facilitate an understanding of the topic are eliminated. The remaining statements are referred to as the *horizons* of the phenomenon. Moustakas (1994) refers to the horizons as the “. . . grounding or condition of the phenomenon that gives it distinctive character” (p. 95).

Horizontalization

Moustakas (1994) states that with horizontalization “. . . every statement is treated as having equal value. Statements irrelevant to the topic are deleted (called

delimiting), leaving only the horizons” (p. 97). According to Moustakas (1988), the primary challenge inherent in horizontalization is to “. . . let everything into consciousness, relevant to the issue, appear in its own way, accepting all of it, receiving all of it, valuing all of it” (p. 114).

Clustering and Thematization

The remaining horizons are then clustered into like categories and grouped into themes that have arisen from the experience. These clustered categories are used to create the individual textural descriptions of the research participant's experience. Moustakas (1994) calls the clustering and thematization “. . . the most essential constituents of the phenomenon” (p. 94).

Textural Description

Textural descriptions are developed for each research participant and compiled into a composite textural description of all of the aspects and details of the phenomena being explored. Moustakas (1994) states: “This is an essential step, putting what matters into a unity of connecting perspectives or components of the whole. This now represents an integrated sense of what is” (pp. 118-119). Moustakas (1988) describes the texture as:

. . . rough and smooth . . . quiet and noisy . . . stationary and moving . . . squeezed in and expansive; fearful and courageous . . . description that presents varying intensity, the whole range of shapes, sizes, and special qualities; time references; and colors. (p. 81)

Holroyd (2001) describes the textural themes as a way to interpret and “. . . rigorously explicate meaning attributed to the phenomena” (p. 3). The end of this phenomenological reduction process results in a textural description for each research participant. The researcher proceeds to integrate those individual textural descriptions

and create a composite representation that conveys the major thematic elements expressed by those interviewed.

Upon completing the reduction phase of the research model, the researcher then begins focusing on imaginative variation, explicating the *how* of the experience, referred to as *noesis*.

These examples, taken from a transcendental phenomenological research study, exemplify and concretize the process of the phenomenological reduction phase. In his study about transcending age expectations, Flewelling (2008), engaged in the horizontalization and clustering process and lists eight textural themes:

1. Attunement
2. Attributions of early experiences
3. Omnipresence of feeling lucky, fortunate and grateful
4. Deliberate maintenance of well being
5. An intentional eschewing of negative influences and experiences
6. Omnipresence of decline and mortality
7. Resistance of expectations of aging
8. Finding meaning in life (p. 127).

After a detailed accounting of these themes, Flewelling (2008) includes three individual textural descriptions. For the purposes of brevity, just one description has been included. It is shortened from the original text.

Edwin is a congenial 87 year-old gregarious person who finds meaning in interacting with others. After spending the early part of his career as a teacher and then school principle Edwin determined that the demands of being a top administrator was too taxing. In addition to finding meaning in interacting with people, Edwin defines himself as a lifelong jock. A baseball player into his mid-60s, Edwin also spent his adult years playing golf. The confluence of Edwin's

interest in people and sports led him to rangering at a golf course after retirement . . . In addition to finding meaning in his athletic activities, Edwin is keenly aware of the health benefits of physical exertion and the exercising of one's mind. (p. 144)

In the above textural quotation, Flewelling (2008) provides examples of some of the textural themes he identified such as attunement, meaning, and maintenance of well being. In the full text version, all of the individual textural themes are addressed in this descriptive process.

Imaginative Variation

In the imaginative variation phase, the researcher begins to consider different meanings found in the research. Moustakas (1994) requires the researcher to look at the data from “. . . different vantage points, such as opposite meanings and various roles” (p. 180). Imaginative variation starts when the researcher engages in a “. . . systematic varying of the possible structural meanings that underlie the textural meaning” (Moustakas, 1994, p. 99).

Moustakas describes the process of free fantasy variations where the researcher considers the structural components that bring forth the textural characteristics of the data. He asks the researcher to view the data through the lens of seven universal structures, including: 1) temporality, having to do with time, past, present or future; 2) spatiality, or, how space is perceived; 3) relationship to other; 4) relationship to self; 5) causality, which is the perception of cause and effect; 6) bodyhood, which is concerned with bodily sensations and awareness and the relationship to the world or corporeality; and 7) materiality, or the physical description of emotions, feelings or events.

Temporality

Moustakas (1994) describes temporality as:

Directly related to one's life; connected to future directions and possibilities, from which past experiences and associations are awakened, which leads to present projects, interests, and creations. The person's relationship to time is of the essence . . . the sense of finishing what one starts is called datability of time. He specifies three others characteristics of time: its significance--there is always time for something; its expansiveness--it can be a continuous project conducted over an evening, a week, or even a year; and its public character--its understanding for people who are intimately related . . . our relationship to time--whatever it may be at the moment--is the basis of our dwelling in the world. (pp. 55-56)

Examples of temporality include statements given by research participants such as, "Time seemed to stand still;" or "Time passed quickly." Temporality could also be specific references to dates and time.

Spatiality

Benswanger (1979) divides space into four separate structures:

1. *Attuned space*: A person's feeling of comfort in a particular space. If one is feeling secure in a space they may perceive it differently.
2. *Activity*: In this case, space is related to movement. How an individual moves and interacts with the space or environment influences their boundaries, direction and sensory awareness.
3. *Spatial characteristics*: Considers a person's unique orientation to space. This would depend on their unique characteristics such as height, weight and whether they were right or left-handed, which could impact their experience and relationship to space. A short person might describe something as just out of their reach, whereas a taller person would describe the same experience as having to bend down to grab an object close to them.

4. *Organization*: This orientation to space begins early on and is formed by a child's primary caregiver. A research participant may view space as a way to organize or categorize their environment versus a person whose early experience of space was chaotic and disorganized.

Relationship to Other

Pollio, Henley, & Thomson (1997) divide this structure into three principle categories: relationship, comparison, and benefit. In relationship one can only understand oneself when engaged in a relationship with another. An example of this might be, "When we were together I felt right with the world" or "He was the world to me," (Pedalino, 2004, p. 78). All relationships can act as prisms to understanding the self. Comparison serves the purpose of more fully understanding oneself when compared with the other. Social norms and stereotypes may emerge in this category. Pedalino (2004) provided this example, "Compared to her I was ugly. She was tall, blond and thin and I was not," (p. 78). Lastly, is the category of benefit. This structure addresses the degree in which the other meets one's needs. However, this structure may also address the lack of benefit in relationship. The other may be selfish or withholding. Pedalino (2004) exemplified these types of statements with the following examples, "He completed me and fulfilled all my needs" or "He was a selfish bastard who never gave me an ounce of love, warmth or compassion," (p. 80).

Relationship to Self

Pedalino (2004) describes relationship to self this way, "To have a relationship with one's self, an individual engages in such processes of self-reflection, self questioning, self-confronting, self-awareness, self-relatedness, self empowering, and self

resistance” (p. 81). Examples for this structure might be, “I hated myself for what I could not achieve” or “I could not look in the mirror; the sight of my own reflection made me sick” (p. 81).

Causality

According to Bach (1998), there are three ways to categorize causality or cause and affect relationships: chance, determinism, and free will. Chance is characterized as unpredictable and random. Determinism implies the unfolding of natural events that the individual has little or no control over. Conversely, free will allows the research participant to view their experience as one he or she had control over and could manipulate and influence. Bach provided the following examples of deterministic causality. “I felt powerless. I could do nothing to stop the feeling” or “We were meant to be together . . . it was only a matter of time before we met and fell in love,” (p. 58). An illustration of chance in causality could be, “It was pure luck that we met that day” or “Had I not had my appointment in that building on that day at that time we never would have met in the elevator” (Bach, 1998, p. 59). Lastly, free will causality might sound like, “It was by sheer will that I got myself out of that bad relationship. I planned, saved and waited until the right time. I left him in the middle of the night and never gave it a second thought. I was out of there and bound for better things” (Bach, 1998, p. 59).

Bodyhood

This structure refers to one's experience of his or her body in relationship to their environment. Bach (1998) provides examples of bodyhood, “I had no physical energy . . . My hair fell out . . . My blood pressure was elevated . . . It taxed my body” (pp. 62-63).

Materiality

According to Ellenberger (1958), this structure includes how one experiences or articulates the matter in their surroundings. It refers to the basic elements or materials that exist in nature such as earth, fire, water, and air. Giorgi (1994) explains how a person describes and understands his or her relationship to external stimuli in the environment. Examples of materiality might be, "I felt cozy and warm sitting by the fire wrapped in a soft woolen blanket" or "She was like a breath of fresh air."

According to Moustakas (1994), the researcher identifies the primary structures present for each research participant. Each structure referred to provides a unique view from which the phenomenon is experienced for each participant. The researcher creates individual structural descriptions that integrate all the structural descriptions of the experience. As the final step in imaginative variation, "The researcher will create a Composite Structural Description that integrates all the individual structural descriptions into a group or universal structural description of the experience" (Moustakas, 1994, p.181). Once the composite structural description is completed, the researcher combines all the relevant thematic data into a synthesis.

Synthesis

The last phase of the Transcendental-Phenomenological model is the *synthesis* or the integration of both the textural and structural composites. Moustakas (1994) instructs the research to, ". . . intuitively-reflectively integrate the composite textural and composite structural descriptions to develop a synthesis of the meanings and essences of the phenomenon of the experience" (p. 181). According to Holroyd (2001), the synthesis

is defined as “. . . the summary of the interpretive themes to produce an in-depth picture of participants' experience of the phenomena under investigation” (p. 3).

The synthesis serves as the final compilation of the essences mined in the data. It is the coming together and comingling of relevant themes as they pertain to the research question. Moustakas (1994) states that the synthesis brings together “. . . the what of the person's experience and the how in such a way that its nature and meanings are embraced” (p. 128). Moustakas further states that in “. . . developing the synthesis, it is important to keep in mind the horizons and invariant themes and the fundamental structural descriptions” (p. 181). These components are important to consider because, as Moustakas (1994) indicates, “The synthesis is not a summary but an intuitive, imaginative creation of the essence of the phenomenon” (p. 129).

Summary

In this chapter, the differences between quantitative and qualitative research methods and theory were reviewed and a detailed description of the Transcendental-Phenomenological model was provided. The next chapter provides details as to how the model was applied to the current study. Specifically, it will offer an overview of the methods and procedures utilized for organizing and analyzing the research data.

CHAPTER IV

Methods and Procedures

In this chapter, the methods and procedures used in the preparation for research, gathering data, and organizing and synthesizing the data are described. All letters and forms referenced in this chapter are found in the appendixes.

Methods and Procedures in Preparation for Data Collection

Prior to beginning any phenomenological investigation, the researcher must formulate a question. The present study examines the question, *How does an adult with Asperger's syndrome experience having a special interest?* The relevance of this research endeavor is to understand, as a clinician, the importance of having a special interest--not as pathology, but from the research participant's tacit understanding of him or herself and his or her internal drive toward his focalized interest.

As stated in Chapter I, my curiosity and inspiration for the research question pertaining to Asperger's syndrome and special interests was inspired by and began with my troubled relationship with my eldest and socially odd brother, my fascination with the neighbor boy who spent hours learning about the sprinkler system, and lastly, an identified learning disability that created a desire to associate myself with others who demonstrated intellectual greatness. These three life events resulted in an awareness and attunement toward certain individuals who possess talents in specific domains, yet have great difficulty with social interactions.

My question began as, *What is it like to have Asperger's syndrome and a dominating special interest?* This was the starting point for my research investigation. After many discussions with my doctoral chair, advisors, and other clinicians who work

with the AS population, I refined my inquiry to: *How do adults with Asperger's syndrome experience their special interests?* Utilizing this question as the foundation of my phenomenological study, the research process was begun.

Research participants selected for this study were required to meet the following criteria: 1) no younger than 18 years of age; 2) received a diagnosis of Asperger's syndrome from a medical or psychological professional; and 3) possess a self-identified special interest.

Potential research participants were located and identified through several means. The researcher contacted a number of professionals such as social workers, developmental pediatricians, and psychologists working with adults with AS. These communications took place either by email, letter, or phone, and a description of the study was provided (Appendix A). Upon receiving the initial communication, a discussion with the professional typically ensued regarding any possible participants that he or she knew and thought were appropriate for this study. The colleagues either posted Appendix A in a waiting room in their clinic, or contacted people directly if they believed them to be suitable for the study. If potential participants were contacted directly, the professionals gave them the pertinent information outlined in Appendix A, which included instructions on how to contact the primary researcher if they were interested in being interviewed.

This process led to nine scheduled interviews. The remaining three participants were identified based on word of mouth referrals from individuals who were previously interviewed and knew other individuals with AS who met the criteria for this research investigation.

All research participants made the initial contact with the researcher via telephone or email. The initial interaction between the potential research participants became an informal screening process, where the researcher ensured that the participant was at least 18 years of age, had a diagnosis of AS made by a professional in the medical or psychological field, and possessed a self-identified special interest. During the initial phone screening the researcher also sought to determine if the potential participant would be able to communicate with relative ease and thereby qualify for the study.

The potential participant needed to demonstrate an ability to talk, describe or visually demonstrate the nature and development of his or her special interest. The researcher also needed to assess whether the potential participant could comprehend the basic questions asked during the interview process. Based on the repartee that took place during the initial phone conversation, the researcher decided whether a particular participant had expressive or receptive verbal difficulties that might be challenging during an interview. If so, the participant was encouraged to bring pictures, graphs, and other visual props to assist in illustrating his or her experience. If the researcher noted receptive language challenges, a note was made to provide extra provisions, such as writing implements or a computer to assist in communication during the interview. Assistive technological devices were never needed or used for this study.

Upon completing the phone conversation, an interview date was set for those that met the participant criteria. The following list of guiding questions was provided to research participants prior to the interview for their reflection and preparation:

1. What was your first special interest? Describe what stood out for you about it.
2. Describe the relationship you have to your special interest.

3. What emotions or bodily responses, if any, do you experience while talking about or engaging in your special interest?
4. When you are engaging in your special interest, what other things are you aware of in your immediate environment?
5. Has engaging in your special interest affected your life? If so, how?
6. What would your life have been like without your special interest?
7. Tell me about your special interest in connection to relating to others?
8. How do you think that others in your life experience your special interest?
9. Is there anything I did not ask you that you would like to mention now?

Once the appointment was set, each research participant was sent via email or through the United States Postal Service, an invitation letter, an Informed Consent form, and a detailed explanation of key terms pertinent to the understanding of the nature of the study (Appendices B, C, and D). The Informed Consent form was approved by the Michigan School of Professional Psychology Human Subject Review Board before any of the interviews occurred. The Informed Consent provided detailed information on the nature and topic of the study and the risks and benefits of participation. In addition, explicit directions were provided in the event the participant decided he or she wished to withdraw from the study. Moreover, this document explicated the issues pertaining to confidentiality and the lengths taken to protect the identities of research participants. Contact information for the doctoral chairperson and principle researcher was provided for further questions or concerns. All informed consent forms were returned to the primary investigator prior to the interview or at the time of the actual meeting.

Methods and Procedures for Data Collection

In total, 14 interviews were scheduled but only 12 were completed. Two of the interviewees were not able to participate due to illness or family obligations. Nine of the 12 interviews were held in private conference rooms located in local libraries in metropolitan Detroit. The remaining three interviews were conducted via telephone, as some research participants lived in other states or countries. The researcher conducted telephone interviews in a locked room within her home. Total privacy was created and research participants were assured that no one else was listening or could hear what was being said during the course of the interview. The researcher recorded all interviews using an Olympus digital voice recorder purchased solely for the use of this study. No full names were used during the recording of the interviews and all research participants were referred to by first name or first initial in order to protect their identities.

Prior to starting each interview, the researcher reviewed the Informed Consent form with the research participant to ensure that he or she understood the parameters of the study, issues of confidentiality, and how to contact the researcher with questions or concerns after the interview concluded. The researcher allowed time for research participants to consider the information on the form and formulate any questions. Questions were addressed directly; if no questions emerged, the informed consent document was signed and dated by both participant and researcher and the interview ensued. All research participants interviewed via telephone were required to mail their signed consent forms prior to the date of the scheduled interview, and the same opportunity for questions was provided as in the face-to-face meetings.

Interviews were conducted utilizing an informal conversational style (Patton, 2002). There was some concern about the research participant's ability to respond to an open-ended interview style. It is written that individuals with AS have difficulty with free flowing dialogue and their interactions tend to be one-sided (Attwood, 2003). As such, the primary investigator considered the use of a more structured interview approach. However, after completing the pilot study it was determined that the researcher would utilize a list of guiding questions as the primary structure for the interview. The interview style morphed into a combination of a structured and open-ended approach based on the needs of each research participant. Douglas (1985) describes this style as creative interviewing:

Creative interviewing is purposefully situated interviewing. Rather than denying or failing to see the situation of the interview as a determinant of what goes on in the questioning and answering processes, creative interviewing embraces the immediate concrete situation, tries to understand how it is affecting what is communicated; and by understanding these effects, changes the interviewer's communication processes to increase the discovery of the truth about human beings (p. 22)

Utilizing this creative interview process, the primary researcher allowed a certain amount of flexibility in order to capture the essences of the experience. The research participants received the guiding questions prior to the interview and they were encouraged to prepare in any way they felt comfortable. These pre-planned guiding questions served as the structured aspect of the interview. If the topic of conversation strayed too far from the research question, the primary investigator simply referred back to the list of guiding questions. The primary investigator engaged easily with each research participant in 11 out of 12 interviews. At no time did the conversation seem to lag nor did the participants seem unable to respond and engage fully with the questions.

The researcher began each interaction with simple inquiries about individual histories, family background, and a request that the research participant describe how they see themselves. These questions served two purposes: 1) to establish rapport and help the research participant become comfortable talking in front of the researcher; and 2) to create a wealth of demographic information on all the participants.

Once the participant was ready to begin the interview, the researcher asked the seminal question, *How does an adult with Asperger's Syndrome experience having a special interest?* Time was allowed for the research participant to explore the topic independently and fully.

Some research participants' answers became too tangential and did not pertain to the focus of the investigation. At these times, the researcher referred back to the list of guiding questions and politely returned the conversation to the topic at hand. Summarizing statements were made by the researcher to seek clarification and elucidation on each main subject.

Reactions from the research participants regarding the interview process and the experience of being questioned about their special interests varied from enthusiasm and joy, to frustration and concern at the inability to express thoughts and ideas cogently. Some of the research participants continually ended their statements with a question such as: "Did you understand what I said?" or "Does that make sense?" These participants seemed anxious about their communication skills. In these instances the researcher made extra attempts to clarify her understanding of the concepts that the research participant was attempting to convey.

Most of the interviews took place over a 60 to 90 minute time period. The interviews were concluded with the statement made by the researcher, "Is there anything you wanted to add that has not been said up to this point?" This inquiry was typically answered in the negative; however, some research participants did make additional statements about their special interests or provided pertinent information about themselves. The interview ended when the researcher was satisfied that everything the participant wanted to share had been covered. Overall, the interview process provided rich data regarding the experience of adults with AS and their special interests.

Upon completion of the interview, each participant's voice recorded conversation was transferred from the digital voice recorder to a compact disc (CD) and sent to a transcriptionist to create a text transcript. This was done in preparation for the phase of data analysis. All CDs were secured in a locked desk drawer in the researcher's home office. The downloaded data was then protected on the researcher's home computer and defended by the latest antivirus, spyware, and firewall protections.

Twelve research participants, eight males and four females, were interviewed for this study, ranging from 18 to 49 years of age. Ninety-two percent of the research participants were Caucasian. Seven were single, four were married and one was divorced. Three out of 12 participants had children; one was unemployed and five had advanced educational degrees.

Research Participants

In this section, a brief introduction to each of the 12 research participants is provided. Research participants are coded utilizing a letter and numerical representation for purposes of confidentiality.

P1 is an African American male in his early 40s. He has two siblings and was raised in the Midwest. Currently, he is married with two children. P1 was diagnosed with Asperger's syndrome late in adulthood. He earned his master's degree in psychology and has worked in an addictions facility. He is now unemployed. P1's special interests are cooking and psychology. He describes himself as a “. . . father, husband, psychologist, poet, writer, six feet tall, 190 pounds, and somewhat athletic.”

J2 is a Caucasian female in her early 30s. She did not receive her diagnosis of high functioning autism until her late 20s. As a child, she struggled with many learning difficulties, including dyslexia. J2's parents divorced when she was five years old. She has three siblings in total; two are from her mother's second marriage. J2 has recently moved out of her mother's house for the first time in her life. She has two jobs, working as a cashier at a local retail shop and at a grocery store. J2 is currently single but indicated she would like to be in a relationship. She describes herself in this way: “I know myself as dependent, did not have friends growing up. I was a hard worker, gave good advice, kind of outgoing but not extremely outgoing. I am down to earth as people have told me. I am caring about other people, very family oriented. I want to have a family and a career.” J2 initially indicated she had interests in scrapbooking and religious music.

J3 is a 37-year-old Caucasian male who received his AS diagnosis in his late twenties. He completed a Bachelor of Arts degree at a four-year university in Ohio. Currently, he is living independently in a rented town house. J3 is employed as a proctor where he administers computerized testing for medical and psychological professionals. This research participant indicated he has been working at this site for one year and four

months; this has been his longest standing job to date. J3 is the youngest of three children; his parents are married and live nearby. While J3 is not currently in a relationship, he indicated he has been involved with one woman in the past, although it only lasted a few months. When asked if he has friends or hobbies, J3 indicated he has a “. . . close knit circle of friends and belongs to the fraternal order of the Knights of Columbus.” J3's special interests include Sherlock Holmes novels, historical dramas, and classical music. When asked to describe himself, J3 stated: “I am a nondescript, normal, everyday person who does the best with what he's got.”

A4 is a Caucasian, 38-year-old, outgoing male. He was diagnosed with AS at the age of 15 but was receiving special education services from the time he was in preschool. He has one younger brother who is married and has two children. A4 has been living independently for the last 11 years. He owns a townhouse close to his family home and his job, as he does not drive. For the last three years A4 has been employed as an executive chef at a well-known neighborhood restaurant famous for culinary foods served in an informal setting. A4 has had a steady girlfriend for the last 10 years and is very involved volunteering at his local synagogue. The special interests of A4 include cooking, country music, specifically, artists that perform at the *Grand Old Opry*, bowling, old television programs, game shows, and collecting autographs. When asked to describe himself, A4 stated: “I am helpful, giving, I help other people. I am conscientious. I am always on time. I hate being late. I like to be ahead of the game; I am always prepared for any emergency that comes along.”

N5 is a 32-year-old Caucasian male. He was diagnosed with AS in the last four years. N5 received special educational services for speech delays and learning disabilities

from the time he was in preschool. Currently he is working toward his doctorate in history. He lives independently in a condominium, which he owns. N5 has been a life-long student, although he has worked part-time as a tennis teacher. He has not been involved romantically and indicates that this is not something he actively seeks out. N5 has written a number of published books in his area of interest and is often employed as a keynote speaker at professional events in his field. N5 has a deep connection with his father. They both enjoy many of the same special interests including jazz, tennis, and making documentaries. N5 did not offer a description of himself when asked.

S6 is a 46-year-old married, Caucasian male. He is a noted author and lecturer in the field of autism, teaches music lessons to children with special needs, and has earned his doctorate in education. According to S6, he received his diagnosis of autism at two and a half years old. He indicated that the team of professionals working with his parents suggested that they have him institutionalized. His mother refused. Currently, S6 lives with his wife of 17 years; they reside on the east coast although he travels a great deal lecturing and promoting his book. The couple has no children. S6 has two long-standing special interests that are his passions: music and bicycles. S6 did not describe himself.

A7 is a 38-year-old single, Caucasian male. He received his AS diagnosis two years ago from a respected psychologist in the Detroit area. A7 currently lives with his younger sister; his mother is deceased and his father is retired. According to A7, he has had a host of jobs in the last decade, including fast food restaurants, retail, and customer service. At this time, A7 is enrolled at a local community college and is pursuing his associate's degree. He is majoring in education and English. A7 lists his special interests

as Popeye cartoons, trains, road signs, and music. When asked to describe himself he stated:

I am just a guy. I have my special interests. At the risk of sounding arrogant, having Asperger's syndrome makes me a little superior in terms of understanding the world. I feel like I am less susceptible to prejudices based on things like religion and cultural differences. Being able to focus on things allows me to have a better understanding of the world, where we have been, and where we are going. Feeling outside of things, I feel like I am more observant than other people. The things I notice, others would never realize.

M8 is a 46-year-old Caucasian, married male. He lives in Great Britain with his wife. He was diagnosed with AS 10 years ago. Currently he is employed as a computer programmer by a small company, and works mostly from his home office. M8 wrote a book that was published on the topic of Asperger's syndrome and employment; he also manages an informational website for individuals with AS. M8 has two brothers; he is the youngest of the three. He and his wife of 11 years have no children at this time. M8 identified many special interests, including: cricket, *Fawlty Towers* (John Cleese movies), cooking, and music. When asked to describe himself, M8 stated, "I am over 6 feet tall and quite athletic. I am moderately academic (three degrees) and intelligent, though not innately so. Character-wise I am genuine, honest and not aggressive."

W9 is a 19-year-old Caucasian male and was diagnosed with high functioning autism in pre-school. W9 grew up with one sibling. He participated in general education at a public school with the help of aides. Throughout middle and high school, W9 was a successful member of the swim team. Currently, W9 lives with his parents and works at a local grocery store stocking shelves. His primary focus revolves around his daily workouts, which he feels helps to keep him healthy. W9 is not currently involved in a romantic relationship but states he would like to have a girlfriend or at least casually date.

His special interests are swimming and lifting weights. When asked to describe himself, W9 stated, "Nice, glasses, strong, high functioning, curious, determined, focused and anxious."

L10 is a 20-year-old Caucasian female diagnosed with Asperger's syndrome in her early teens. She has one younger brother and three older sisters. Currently, L10 lives with her parents. With regard to vocation, she has been employed in a paid position by Meals on Wheels for the past year. L10 is a high school graduate. She has received services from community mental health to assist her in an eventual transition to live independently. During the time of the interview, L10 indicated she is involved in a romantic relationship. She stated in the pre-screening interview that her primary interests are fashion and her family. When asked to describe herself she stated, "Really quiet until you get to know me and then I won't shut up . . . very loyal and hard working."

L11 is a 48-year-old female diagnosed with Asperger's in her late thirties. She was an only child; her father was an engineer but is now retired. L11 has been married for 25 years and has three children. She earned her doctorate in linguistics and is employed as a professor at a local college. L11 also has written books about her experience on the spectrum and is often a paid speaker at conferences on autism. When asked to describe herself she stated:

I have a good sense of humor. I am sardonic, and self-effacing, which helps me with my low self-esteem. I am very caring of others because it is my civic duty. I can walk into a room and immediately go to the loneliest people with the most neurological challenges. I feel like if we don't share then the people who come behind us don't have an easier path. I have no self-esteem left, no ego.

J12 is a 28-year-old Caucasian female and mother who currently resides with her parents. At the moment she is a full-time stay-at-home mother. J12 is a college graduate.

She met her baby's father while in school and was married for a brief time. J12 describes her relationship to her ex-husband as "abusive." She received her AS diagnosis at the age of 20. She was referred for testing and psychological services because, as she states, "I was depressed, had no friends, was teased as a child, not close to my mom and always had difficulty with abstract information." She comes from an intact family and was raised with a younger sister. J12 states her primary relationship has always been with her father. Her special interests include puzzles and stuffed pigs. Currently, J12 indicates that having a child has given her purpose and meaning in her life. She feels she has bonded well with her child and being a mom has made her more outgoing. When asked to describe herself she stated: "I am reserved, quiet sometimes, and I can be outgoing. I am also a very compassionate person."

Methods and Procedures for Organizing and Synthesizing the Data

The interview data consisted of more than 15 hours of recorded information. The voice-recorded data was transcribed into more than 300 pages of typed material. Once the primary investigator received all the typed data, the process of phenomenological reduction took place. To refresh the reader's memory and preview how the data will be handled and presented in Chapter V, the researcher will now revisit and briefly summarize the steps in the phenomenological reduction process.

The phases of the Transcendental Phenomenological model are as follows, 1) *bracketing*, where the data is filtered to contain only information that addresses the key question being studied; (2) *delimiting*, which deletes any overlapping or repetitive statements that do not pertain to the question at hand; 3) *horizontalization*, where all statements given by research participants are included for consideration; 4) *clustering*

and thematization, which addresses the organizing of the horizons into groupings of like themes that give shape to the experience; and 5) identifying *textural themes* that uniquely and descriptively reveal the nature of the experience. Following is a detailed explanation as to how the researcher applied the research model to the investigation and analysis.

Prior to each interview, the researcher engaged in *epoche* and attempted to release all preconceived notions and outcomes and be present and fully engaged with each research participant. To accomplish this, the researcher spent a moment in silence before beginning each interview. For telephone interviews, the researcher cleared her office desk, sat in her cushioned chair and took a series of deep breaths to clear her mind. The researcher meditated on the intention of freeing her mind and willing herself to be open to the person and his or her experience. A similar process of *epoche* took place prior to the interviews conducted in closed rooms at the library. This was done by checking to make sure the recorder was working, by clearing a space on the table, and by taking numerous deep breaths to relax and refresh before the research participant entered the room.

Moustakas (1994) states the purpose of phenomenological reduction is to peel away the extraneous findings and uncover the “. . . descriptions of things just at they appear and to what is horizontal and thematic” (p. 91). Moustakas did not determine for the researcher the exact process of reducing the text. At this stage, the primary investigator had the opportunity to use her creativity in order to uncover the horizons. In this study, the researcher printed each of the 12 transcribed, full text interviews. She purchased an oversized three-ring binder and dividers and assigned a number to each interviewee. She then filed each transcript under its corresponding research participant

section of the binder. A folder was inserted in each participant's section of the binder to hold all the identifying criteria and signed informed consents. This notebook housed all the initial data for this study. When not being utilized it was kept in a locked drawer in the researcher's home office.

Next, the primary investigator read through each one of the interviews and on a separate piece of colored paper, wrote down all the quotes or horizons that seemed germane to the study. Once this was done for all of the 12 research participants, the researcher bracketed and listed all the horizons captured in the data. The bracketed horizons were then highlighted and listed on a separate sheet of paper. The researcher allowed a few days to pour over the data and fully examine and tease out all possibilities. See Appendix F for a full accounting of all 22 horizons that were identified during this initial stage.

A table was created by the researcher, which listed all the identified themes. A check box provided next to each theme served as place to indicate whether or not that horizon occurred in each particular interview. The top 10 most frequently occurring horizons became the focus for consideration and the less frequently occurring horizons were delimited or set aside.

Once the extraneous themes were delineated, the researcher met with her doctoral chair. Together they examined the remaining bracketed horizons and began to cluster them into central themes. After a lengthy discussion, the primary textural themes were identified. The horizons that became the textural themes comprise the noema or the *what* of the research participant's experience. Once the textural themes were determined, the researcher created three individual descriptions that best captured the textural themes.

Following preparation of the individual textural descriptions, the researcher created a composite description that integrated and created a “. . . universal composite textural description” (Moustakas, 1994, p.180).

Upon completing the reduction phase of the research model, the researcher began the process of engaging in imaginative variation. Here the researcher viewed the data through the lens of seven relationship-to-world universal structures, including: 1) temporality; having to do with time, past, present or future; 2) spatiality; how space is perceived; 3) relationship to other; 4) relationship to self; 5) causality; which relates to the perception of cause and effect; 5) bodyhood; 6) corporeality; which addresses the body in relationship to the world; and lastly 7) materiality; the physical description of emotions, feelings, or events.

The researcher once again reviewed the participants' data. Utilizing the horizons identified in the first phase, the primary investigator categorized the results into the seven universal structures. To confirm these structural concepts, the researcher took direct quotes from the transcripts that represented the primary and most significant universal structural themes. These themes comprised the noetic aspect, or the *how* of the experience of having a special interest. This aspect of the model illustrated the way in which the research participant lived the experience. At this state the researcher must be engaged and imagine from different angles all the ways in which the research participant described his or her lived experience, thereby uncovering the truth of the experience. Once the structural experiences were clustered, the researcher created three individual structural descriptions that were then combined into a composite description that

embodied the total structural explication of how an individual with AS experiences having a special interest.

Lastly, the researcher entered the stage of synthesis or the integration of both the textural descriptions and structural relationship-to-world composites into a written synthesis. Moustakas (1988) states: "The aim is to bring together the *what* of the person's experience and the *how* in such a way that its nature and meaning are embraced" (p. 83). The composite and textural-structural descriptions represent the research participants' combined essence of the experience.

Summary

In this chapter, the methods and procedures to collect, organize, and analyze the data were delineated. The ethical measures taken to inform research participants of their rights and the measures utilized to protect confidentiality were discussed. Also included was a brief demographic introduction to the research participants and a summary of the phenomenological reduction process. In the next chapter, the research findings are presented.

CHAPTER V

Presentation of Findings

In this chapter, the data that illustrates how adults with Asperger's syndrome experience their special interests is presented. First, the textural themes identified from the interviews are described. The textural themes represent the feelings associated with the *what* of the experience. The three individual textural descriptions that embody the primary textural themes are provided, as well as a composite description that illuminates the universal textural themes, or the noematic aspects, of the experience. Next, the data is presented according to the seven universal structures, also referred to as the noesis. These structures include: *relationship to self, relationship to other, materiality, temporality, causality, spatiality* and *bodyhood*. Once all relevant structures are considered and discussed, three structural descriptions are specified, followed by the composite structural description, which highlights the main structural themes. The final step brings together the noema, the *what*, and the noesis, the *how* of the experience. The synthesis integrates the thematic essences found in the data.

The verbatim material used to illustrate the themes is not presented in its entirety. Kurek-Ovshinsky (2002), in the presentation of research findings stated, "Quotes are telescoped and eclipsed examples from the transcribed narratives, representing striking features of the underlying experience" (p. 87). This excerpt describes how the clustered horizons will be presented in this chapter. In this section, significant quotes are used to capture the research participant's experience of his or her special interests.

Textural Themes

Each of the three textural themes was found in a minimum of 6 of the 12 interviews. The coded horizon table (Appendix F) indicates that the researcher directly identified a theme as being present in the interview. However, if a specific theme was not present, it does not mean that the particular experience is absent from the research participant's understanding or awareness. It simply conveys it was not discussed during the interview.

To arrive at these textural themes, the researcher was immersed in a constant process of epoche while engaging in phenomenological reduction. Moran (2000) stated, "Husserl characterized epoche in many different ways: abstention, dislocation from, or unplugging or exclusion of the positing of the world" (p. 147). To attain objectivity, the primary investigator viewed the data before her while trying to set aside all other life distractions, influencing thoughts, and preconceived notions that resulted from previous studies.

According to the Transcendental Phenomenological model, the textural themes represent the *what* of the experience. The textural themes are found directly in the data and explicate the primary essences of what it is like for adults diagnosed with Asperger's syndrome to have a special interest. The three textural themes identified were: 1) coping, 2) addiction, and 3) valued and respected.

Coping.

Coping, for the purposes of this study, is defined as successfully managing a difficult situation. The research participants utilized their special interests as a strategy to maintain their equilibrium in a world they often found unfriendly and overwhelming. The

special interests became a way to: 1) anesthetize or escape; 2) provide calming; 3) focus attention; and 4) maintain predictability by being object-focused.

Anesthetize or escape.

P1's special interest was psychology. He worked as a counselor in a chemical dependency clinic and described his singular interest as a way of self-medicating to escape the stress of living in a world where he felt constantly misunderstood.

I look back at the experience [working with chemically dependent individuals] and see us [as having] exactly the same thing; though I don't mean that we are necessarily taking foreign substances and abusing but we are definitely charged with having to live our life on a daily basis by having to deal with and address being different; and people seeing us different and being called names or being misunderstood on a daily basis and having to cope with and that's why anxiety and depression is high for us. Having to deal with that is definitely a huge aspect of living with Asperger's, because we are clearly misunderstood.

A7, whose early special interests included watching cartoons, reported that he could escape the confusing world and protect himself from being misunderstood by transporting himself into a different world, a predictable place, a cartoon land.

I am not dealing with the teacher; I was not dealing with the classroom. I did not have to sit at a lunch table with a bunch of people who did not get me. I did not have to try and explain myself, I did not have to try and understand them. I was watching something I knew.

Focus attention.

For J4, his special interest was music; it provided a multitude of ways to help him focus, organize and calm himself. "I was scattered and had trouble paying attention," yet he could concentrate on the interest and his attention span would improve. He indicated that, "Music helps me with the flow of words" and "Listening to classical music disciplined my mind." J4 stated numerous times that his ". . . different interests make

[me] lose myself and help with concentration.” He stated, “Special interests provide the structure and I thrive.”

A7 indicated that he used his special interests as a way to focus his attention away from the social milieu, which proved confusing.

Not understanding the way people interconnect contributed to me becoming obsessed with my special interests. There was no bullshit with whatever I was focused on at the time. If it was 4:00PM that meant Tom & Jerry were on and that I was going to watch Tom & Jerry . . . we would see something that would be diverting and that we could watch and focus on.

M8, whose special interest is croquet, revealed that his special interest provided him with an ability to focus, which could be a challenge for him.

I do have difficulty focusing. I will flip from different things. One minute instead of just finishing and concentrating on that I will flip to something else. I think that's because part of the time I have difficulty maintaining my concentration for some time. Croquet, an American would think is a very slow game, but I can sit in front of the television and I can watch it all day because I can become quite engrossed in it and I don't get distracted. It's a really calming experience for me.

J4 differentiated between special interests that helped him to focus and those in which he became so absorbed or hyper-focused that he could forget about the food he had put on the stove.

[Some interests] would put me on a focus but I would try to keep other things in mind; let's say I had a pot of coffee going or something on the stove. I try to keep [an awareness of] the environment around me because of the simple fact I could lose track.

Conversely, J4 indicated other special interests, such as listening to music, helped to organize and regulate his attention and focus.

N5 referred to this hyper-focusing as tunnel vision. He stated that while watching his game shows, “I remember that it got me extremely tunnel-visioned; like my whole

day was focused around the game show and waking up at 10:00AM to watch the first game show.”

Utilizing the special interest as a way to focus one's attention was a dominant theme for 10 of the 12 research participants. The verbatim material elucidated the ways in which the participants engaged in activities that helped them cope in a world where often times they had difficulty. Conversely, some of the activities could become so engrossing that the research participants became overly involved and unable to keep track of important aspects in their environment.

Maintaining predictability by being object focused.

The concept of coping was a dominant theme for J2. She described her interactions with others as “chaotic.” J2 sought to gain more control and thereby a sense of calm or peace in her environment by engaging alone in her special interests. Her special interests provided an opportunity to predict and control all aspects of the solitary game she played. Because J2 did not always understand what people were saying or asking of her, she began to spend more time playing with her objects or animals. She stated, “[Stuffed] animals cuddle you and don't talk back.” J2 indicated that by isolating herself she could gain the predictability and an overall sense of calmness she craved:

I did my own thing, I was in a comfort zone and so I wasn't around like the big social world because I would feel very alone . . . I understood what was going on, that was my fun time, my play time when I was a kid compared to the adult world or the neuro-typical world where everyone is talking.

J2 felt a sense of predictability and calmness while playing alone. Her interests became a way for her to escape the world of language and unpredictable demands placed upon her when socializing and interacting with others.

S6 described his love of bicycles. He spent large amounts of time collecting information about the mechanics of bikes. To his parent's displeasure, his interests were object focused and solitary.

I remember one time being hyperfocused on bicycles. What I could do is I could look at a bicycle and have the whole bicycle catalog in my mind. It only took about two seconds and I'd have all the data that you were talking about . . . what the gear ratios were, what the components were, how many gears it had, how much the different components weighed, how well they worked together and how big the bicycle was and things like that. I was doing one of these data dumps to my parents and their response was I should really spend more time thinking about the person on the bike, not just the bicycle itself.

S6 clearly demonstrates a talent for memorization, but much of his energy is absorbed by objects, versus being focused on people. This can be seen as an inherent fascination. Yet it also provided a way for S6 to avoid connections with others that could be confusing and less rewarding. The complexity of human interactions possessed a massive amount of variables that required a certain skill set, whereas memorizing statistical information was satisfying because it placed no social demands upon him.

The textural theme of coping revealed four primary components for the research participants. The world proved to be a place where they often felt misunderstood, overwhelmed, unfocused, anxious, and unable to predict and navigate, especially when it involved social interaction. Therefore, they devised strategies to cope by engaging in special interests that allowed them to: 1) *anesthetize or escape*; 2) *provide calming*; 3) *focus attention*; and 4) *maintain predictability by being object focused*. The primary challenge that arose was that while engaging in the special interests they could become so absorbed that they would lose track of other important aspects of their environments.

Addiction

Many of the research participants spoke of a heightened sense of excitement while engaging in their area of interest. Aspects of bliss, physical reactions, which included sexualized responses and euphoria, were evident in the data. If viewed through the lens of addiction, the special interest becomes like a drug. The research participants were intoxicated and stimulated while engaged in their special interests, comingled with an almost religious-like fervor. Yet along with the "high" the research participants experienced, they also noted feeling addicted to, ruled by, and obsessed by their special interests.

For some, the excitement translated into bodily response such as hand flapping or jumping. N5 described a deep sense of excitement, which manifested itself as a physical reaction. He characterized the time spent watching game shows and tennis matches:

. . . an inner sanctuary, like a temple almost; [it was just] me and my TV. If something exciting happened like a contestant winning a car for example, I'd jump up and down and clap . . . I was real physical during this time.

Even when nothing overtly exciting was happening during a tennis match or game show, N5 would pace around the room in anticipation:

Like I remember what would really get me excited is like two minutes before the game show started, there would be like a sense of anticipation and I'd pace back and forth and the minute it would come on and then I would start jumping up and down like the opening credits or whatever. And then I would start pacing once the game show started and then when something happened I would jump and clap.

A7 explained his heightened and highly excitable response to certain music:

There will be . . . okay here we go, this is probably the oddest thing I do when I listen to music. There are sometimes certain songs that will have what I call a best part where my state of Aspyness reaches . . . my state of Aspergery excitement or whatever you want to call it reaches its pinnacle or its apex . . . I don't want to call it a sexual effect because it is more but there is a mental aspect to that. Have you heard the phrase intellectual orgasm? It is not far off.

For the above two research participants, the heightened state of excitement was often paired with listening to or watching something repetitiously. However, L12 could hear a soothing sound just once and become aroused:

I would do anything for a soothing voice. I would have sex for a soothing voice. I am not even kidding. If you were to whisper in my ear, that would get me, that would get me, it would almost lead me to an affair. If I hear a voice that is calm and collected and soothing . . . I would melt. There is nothing like a soothing cowboy voice on a horse, I would give everything that I own. It is hypnotic.

In the above quotation L12 describes a sexualized response to certain sounds, like actor John Wayne's voice, that stimulated a sense of being altered or transported. Other terms such as "inner sanctuary," "temple," and "elixir" were similarly used by the research participants to portray a reverence toward their special interest.

Some of the research participants referred to the down side of having their special interests become "obsessions" or "addictions." One participant portrayed himself as a "slave" to his special interest. A4 explained that recording and documenting all the artists who performed at the *Grand Old Opry* was his ". . . number one priority." He stated, "At times it ruled my life." Another participant in the study described himself as "totally obsessed."

N5 described his fascination with watching tennis matches or game shows:

The game shows that I was interested in always took precedence over everything else. It sort of became an addictive thing in that the more times I would watch a certain point played by Bjorn Borg or John McEnroe, the more times I'd want to watch it. So it is not like I've watched it 25 times and that's enough; no I would want to keep watching it over and over again. It was like a drug. With me it was the more I did it the more I wanted to do it and it became a never ending cycle.

L11's special interest was bicycles. She loved to ride and tinker with her bike.

Early on she made a decision that she would ride her bike 10 miles per day and no more.

So I would ride my bike all around the neighborhood and up and down the streets until my speedometer read 10 miles and then I had to get off my bike and carry it the rest of the way home so that the tachometer did not go over the 10 miles until the next day.

L11 emphasized the importance of only riding 10 miles. She stated, "It is like an addict. If you don't the anxiety is just overwhelming and you get physically snappy, crabby. It is not worth it so I just gave in to it because it brings satisfaction."

The theme of special interests as an addiction presents a paradox. The adult with AS viewed and responded to their special interest with exhilaration sometimes paired with an almost sexualized sense of pleasure. They spoke of their special interest with a religious-like reverence, yet they simultaneously characterized their responses to their special interests in terms of being addicted to them. The special interest, the very thing they cherished, began to rule their lives.

Valued and Respected

Eight of the twelve research participants spoke of the importance they placed upon being valued and respected. The development of a special interest may be viewed as a direct response to the human need to be appreciated, esteemed, and noticed. Attwood (2003) indicated that individuals with AS were often characterized as "little professors" and that they were known to gather and memorize encyclopedic amounts of information on their selected subject matter. For the adult with AS, being valued included being known as the local expert or the person who could provide answers. Gaining expert status, according to the research participants, was the primary avenue used to earn the appreciation of others. It also held a certain amount of status and could provide opportunities to be recognized, appreciated, and admired.

P1, whose special interests included cooking, psychology and health, stated:

I think it just gives us something to put our mind on . . . special interests give us something that is familiar to us and then we can delve into it and become our own expert and so since the world gives some value to so-called experts in different fields, you can be an expert in this or an expert in that, people put their thumbs up and say wow this is great. You are the person to come to, to know all about a particular subject and that's something. So because it has value, that has status, and goodness to it, that's what I mean by thanking God for it. If it was not for my special interests, then I would just know a broad amount of attention to everything and then I'd be more scattered brain than I already am.

A4's special interest was the *Grand Old Opry*. He spent copious amounts of time gathering and recording data that pertained to the artists who performed and appeared on the weekly show. When the researcher inquired as to why he spent so much of his time engaged in this activity, he indicated that he wanted to be prepared in case any one had a particular question regarding *The Opry*:

I keep notebooks and each week I put the lineup as it happens into the book, and I do a lot of statistical work. I keep a list of every artist by alphabetical listing of who performs. I keep a listing of every artist and how many weekends they perform during the year . . . list every artist that has been on the portion that has been televised, every artist that has hosted a segment, different things like that. And really it does not have a purpose, but for me it does. If somebody asks me a question, I can almost go back and look it up and have the answer for them almost instantly. If they say, when did so and so make their debut, I know when it was. I can just go look it up and there it is right there in my records. So to somebody else it may seem meaningless, and it is sometimes a lot of work, but I think it is worth all the effort.

Another research participant, N5, described his fascination with maps and roads. What began as a curiosity proved to have additional benefits in that people admired and acknowledged his directional sense as a unique ability that set him apart. He confessed enjoying the attention and felt good when he could assist friends and relatives if they became lost. He acknowledged:

One of the special interests was interstate highways and roads. I remember on a trip to Cleveland, and this might be when I was four or five years old, I was

fascinated by road signs and like in terms of Cleveland 99 miles, this road 2 miles, and then I started looking at maps and I became really interested as to where certain roads began and where certain roads ended. People used to ask me for directions because they knew that I would know where to go and they would say, "Hey, that is so amazing!"

A7 revealed that he enjoyed being known as the "human *Google*" before *Google* was created. He experienced a certain feeling of pride from being able to answer questions about television and radio. While he recognized some people thought it strange that he knew so much about esoteric topics, he sought out the recognition he received from others who were impressed by his unique talents:

Well, I like having a specialized knowledge and I like that people know that I have a specialized knowledge. Before the internet . . . I was like the human *Google* on a lot of things. People would come to me and say, "Hey I saw this movie, was it done by RKO Radio Pictures?" I'd say, Oh yeah, that was an old movie studio in the early '30s or '40s. RKO stands for Radio Keith Orpheum. And some people thought that was really cool and others thought it was weird as hell.

N8, an avid croquet fan, spent the last 20 years collecting data regarding the sport. He memorized statistical information about his favorite game and could impress people with facts dating back to the origins of the activity:

Well, until two years ago, I used to photocopy all the croquet reports out of the Times Newspaper. I started doing it in 1986 and I suppose I did it for 20 years. I stopped doing it a couple of years ago because it got too time consuming and I could not keep up with it, but I have got folders going back 20 years with all the reports of the games, about players and everything like that. I can remember erroneous details about those people and about those games. I can tell you something about every game that has been played in England over the last 25 years easily.

In a final example, L10 reported how her love of fashion and style made her the resident expert among her family members. She proudly asserted, "My whole family asks my advice on what looks good."

The majority of research participants spoke of the desire to be esteemed and cherished. Each of the above quotations provided insight as to how adults with AS utilize their special interests as a means to gain admiration among their peers and family.

Individual Textural Descriptions

The textural themes of coping, addiction, and being valued are followed by three individual textural descriptions that bring to life the noematic aspects of how an adult with Asperger's syndrome experiences having a special interest. The individual textural themes are presented in sequence as they were revealed during the interview. This will provide the reader with a greater appreciation for the research participants' thought processes and how they connected one thought to another.

Individual Textural Description: P1

P1, an African American male in his mid-forties was diagnosed with AS later in life. He earned an advanced degree in psychology and previously worked in a facility that treated adults struggling with addictions. P1 is married and the father of two children. He was unemployed at the time of the interview. His special interests began with a fascination with dinosaurs and today include psychology, cooking, and issues relating to health.

P1 has struggled throughout his life because he was different. He had challenges focusing his attention, but his special interests provided a way for him to "anchor" himself.

It is like attention deficit, it is kind of like having the channel change all the time, and you can no longer be focused on one specific programming from beginning to end because you just keep changing the channel. Special interest is like saying okay, on this particular hour I [am] choosing to think about baseball . . . I can place my mind on it and stay there and it calms me and I can deal with it, when everybody else is losing their minds.

His special interests represented a way for P1 to overcome feelings of “anxiety and depression” in a chaotic and confusing world where he often felt misunderstood and unappreciated. He admitted to having difficulty maintaining a job and frequently feels misperceived by his family and friends as “lazy, disinterested, and aloof,” which intensifies his feelings of inadequacy and “creates higher and higher anxiety.” P1 indicated that he engaged in his special interests to defend himself from this barrage of criticism.

In response to feelings of ineptitude, P1 sought to find ways to gain favor and respect from others. He loved being able to “delve” into subjects and become an “expert.” Early on, P1 realized that his special interests were something that others admired and appreciated about him; he received positive feedback from teachers and adults regarding his special talents. He indicated that the knowledge he obtained in certain subject matters, as well as his drawing abilities, impressed and influenced people. He stated, “My teacher was very influenced by me because I would be drawing all the time, some pictures and stuff like that, and she thought I was a great artist of some kind.” By burying himself in encyclopedias and books, he could escape the confusing aspects of the social realm and emerge as a specialist, proficient in specific topics. P1 provided an apt example of his expert status regarding his interest in cooking.

Well, not yesterday but the Sunday before that I was making a meal and owners of my house came over. It was a vegetarian meal and she happened to be a vegetarian. And I had a few leftovers. I usually make food leftover so I invited them to sit down at the table and dine with my family. Both owners were delighted with the meal, especially with the nutritious portion of it. One of them mentioned, they are both school teachers. One of the teachers in the local high school invited me to come to her class on Friday to talk with her class about nutrition so I took her up on her offer and did so. And because one of my special interests is nutrition, I basically did not need to do much of any research on that. I just sat up in front of the class and did a two hour long talk on nutrition with very

little preparation. I was able to talk on and on and on about it because I had a fascination of it and I was kind of an authority on those kinds of things based upon my interest in that area . . . the teacher was very appreciative of me.

While the special interest yielded great benefits for P1, he also admitted that he could become overly involved in his special interest and lose track of things around him. He affirmed, "At the time I'm in my special interest I don't see much of anything going on in my environment." P1 relayed an incident where he was left to watch over his infant son. He was simultaneously engaged in watching a baseball game, another special interest at the time. He was completely engrossed in the game and did not see his young son crawling out of his crib.

It happened when my children were young. I was a baseball fan and I guess you could say that that's one of my special interests now. My favorite team is the New York Yankees and watching the game, I was so involved with it, thinking about what was going on, my youngest actually crawled out of the crib and fell onto the floor and I was sitting in front of the crib, and I saw none of it at all.

P1 also indicated that while his special interests have provided social opportunities, he tends to "go on and on and on" about his selected subjects and does not recognize the social cues that the audience has become bored with the topic. He stated, "A weakness of mine . . . taking into consideration somebody might not be interested in this or wanting to know about certain subjects when people around are bored with it."

When asked how he knew people were becoming bored with him, P1 noted that it was a skill he has gained over the years. He provided the following example:

It was just something that came along during the years. It was just something you just kind of learn. For me it was kind of like learning from experience as if I had moved from France and said well French people do this and French people do that. I did not know that all these years of my life until I began to zone in or be more surrounded, or have my eyes open to the specificity of the people I'm around and to be more specific, noticing the gestures that people are giving non verbal.

P1's special interests presented him the opportunity to focus his attention. They offered the prospect of obtaining an expert-like status in certain areas, thereby receiving positive regard and respect from the influential adults in his life. However, his special interests could become all consuming, and P1 was likely to lose track of important aspects of his environment, like his young child in the crib. Also, P1 noted that his total absorption in his topic of interest often repelled others and he was not able to read the social warning signs or nonverbal cues regarding his lack of reciprocity. Often, it was not until someone just walked away that he became aware of his mistake. He indicated that most people have a certain "threshold" of interest and, "I would always have more to say" on the topic.

P1 likened this all-consuming absorption in a special interest to being addicted to drugs. He indicated that addicts use their drug of choice as a coping mechanism to alter or change their mood. He believed that special interests provide the person with AS a focus, and with heightened focus, anxiety dissipates and one's mood is altered.

The drug is like a foreign subject that you have to find as appropriate to get and hold and have and use accordingly to give you the boost you need. The special interest is similar to putting you in the kind of mood that you need to [be] in or that you are trying to switch over to, but it is more a focus than a mood. The focus actually creates the mood.

While he "thanks God" for his special interests because they have helped him to focus and brought him esteem and respect from others, he acknowledged that they do present problems in that they can become all consuming. P1 believed the special interests are primarily a coping mechanism for people with AS, but their inherent advantage is that if you pick a special interest with social or scientific relevance, it can provide an avenue for success.

Individual Textural Description: N5

N5 is a 33-year-old male who was diagnosed with Asperger's syndrome in his late twenties. As a child, he presented with a speech delay and had difficulty socializing with his peers. He received therapeutic services at the age of three for his speech delays and made rapid progress. Throughout his school years he received special education services to assist him with academics. He excelled in the sport of tennis and played at the varsity and college levels. Presently, he is working toward a doctoral degree in history. He is a public speaker and has written and published two books. His special interests include game shows, tennis, and jazz music.

For N5, the experience of having a special interest was dominated by the textural theme of coping. Watching game shows and being an active and successful tennis player provided a social bridge. However, the repetitive aspects and esoteric nature of his interests ultimately proved to be socially isolating for N5. He described interests that caused two different responses. On one hand, watching game shows brought forth a heightened state of excitement, while listening to music evoked a calming meditative response. N5 characterized his interests as absorbing and sometimes addictive, but overall he stated that they have helped him “. . . to be a more interesting person.”

N5 indicated that his interest in game shows helped to bring him “out of his shell.” What fascinated and enthralled him were the programs' more esoteric aspects. He was drawn to the predictable mannerisms and voice intonations of the hosts and game show announcers. He remembered listening with rapt attention as the host interviewed contestants, and he would try to emulate them. His goal in life was to become a game show host. N5 believed he sought to find models he could imitate because of his speech

delays. This required an aspect of repetition that allowed him to memorize the vocal intonations and scripts, which he then integrated into his everyday life. For example, he recalled rushing to the door to greet friends or relatives and exclaiming: "Welcome to the home," as if he was Bob Barker welcoming a guest to "Come on down!" N5 reflected about how his interest in game shows has helped him throughout his life:

Bob Barker in particular, I think I tried to emulate him just because he has this real clear voice and he connects with the contestants and I like to connect with people who are asking the questions; even in my daily interactions its almost like I am borrowing aspects of his personality, of the game show host's personality. In some ways it makes me feel phony because it may not be exactly who I am but I think it has helped me, just borrowing these aspects from different people, particularly Bob Barker.

N5's parents encouraged him to develop his interests in announcing, hoping it would lead to a career in radio or television broadcasting. When travelling to family camps or restaurants where regular announcements were made, N5's parents often asked if N5 could be a guest announcer. He was oftentimes allowed to approach the microphone and say things like, "Attention please, there will be a movie in the Pamlin room at 6:00 pm." These types of activities assisted in N5's speech development and created an opportunity to be acknowledged by others, even if it was not a traditional social activity.

Predictability was the primary draw for N5 with regard to game shows. He was not interested in the content, how much something cost or the trivia questions that were asked; rather, his attention was focused on the music that accompanied particular segments, the voices of the announcers, and the scripts that were read during each show. These stable components that comprised each segment were the aspects of the show that N5 focused on while watching:

Things that were exciting to me were the predictable things, so like when the show opened that was exciting to me even though I knew what the opening was going to be, it is the same thing everyday. That's what got me jumping up and down and clapping.

Predictability or sameness was a way of coping that provided a sense of joy for N5. Game shows offered comfort in response to a world that oftentimes proved confusing and stressful. His game shows offered N5 an escape into a world he could count on, a world that was the same everyday. His language delay presented him with many challenges, and the repetitious aspects of game shows served as a pattern that N5 could follow in his social interactions with others.

Watching game shows was a solitary activity for N5; he did not like to be disturbed while watching his shows. He asked his parents to leave the room if they came in while he was watching, and indicated that he knew certain aspects of the show he liked were not of interest to others:

Most of the times that I watched the game shows it was a solitary activity and it is not something I talked about an awful lot. I think deep down somehow I knew that people probably would not be interested in it. Because what I wanted to talk about was not the questions of the game shows, like what they were asking, how much does this thing cost on the Price is Right; it was more of an esoteric aspect of it, which I knew people would not be interested in.

N5 was also very physical while watching game shows. His excitement manifested in bodily responses. He indicated that he almost never sat down while watching the shows; instead he paced in anticipation or jumped up and down while he clapped or flapped his hands:

Like I remember what would get me really excited is like two minutes before the game show started, there would be this sense of anticipation and I would pace back and forth and then the minute it would come on I would start jumping up and down like at the opening credits.

Another special interest that induced this type of physical response was watching video recordings of tennis matches. N5 indicated he viewed certain points in the match over and over again. He stood in rapt attention and then jumped and flapped when the desired part played. He affirmed:

Well I started playing tennis when I was about 10 or 11 and then as soon as I became somewhat good at it, I started really becoming interested in the matches that were on TV. I would tape them and then if I saw that there was really like a good point, a point that was interesting, I'd rewind it, I'd watch it again, I'd rewind it, I'd watch it again, now you wonder why I did not want to have friends over. Who would sit through that? So like the same point I could watch 10 or 11 times and quite honestly I have a DVR, which means I can tape programs off of my TV, and cable box has like a DVD recorder. I still do that to this day. I hit the tennis channel and I watch the matches and if I see a good point, I will rewind it and play it again and I am 30 years old, so I have not grown out of the habit.

N5 cited the repetitious behavior as a theme throughout his life. The predictable aspects of his interests served to excite and capture his attention. He indicated that he could spend all day watching his programs and never become bored. His body was in constant motion, either anticipating or responding to one of the predictable parts in the game show or tennis matches. He described an almost "addictive" quality to his behavior. He stated that watching a "good point" just once was never enough; he had to watch it over and over again.

Conversely, another special interest, listening to music, created a very different bodily response in N5. He stated that he would lie down while listening to Billy Joel or a favorite jazz piece and his body would relax completely.

I had a total opposite reaction when I listened to music as I did to watching television. I was more like tranced. Like listening to Billy Joel, I was kind of like almost having a seizure but not moving or something. I was kind of totally tranced on his music, very still, just totally honed in on his music. That was more like a meditative exercise listening to music, whether it be Billy Joel or the Beatles or whoever; whereas these other things, these repetitious activities were

more excitatory activities. Whenever music is playing it always has this calming effect on me; it is more a relaxing mechanism.

For N5, his special interests provided a haven, a world he could escape to where he did not have to engage socially. He likened the feeling of watching TV with an almost religious reverence. "So it was kind of like an inner sanctuary, like a temple almost, me and my TV." In his inner sanctuary he could be stimulated by repetitively watching tennis matches or game shows; the repetitive nature reassured N5:

The more repetition that I could get from either the game shows that I watched or tennis points that I watched over and over, the more familiar my world was to me and being in a chaotic world all day, going to school and getting made fun of and having [people] tell me my work is just not good enough, this was like a comfort for me. Okay, now I can [go] home watch my tennis points over and over again. It was something I looked forward to like a refuge.

Although watching television evoked an excitatory response, it still served as a coping mechanism for N5. If he wanted to put himself into a peaceful "trance or meditative state" he could listen to music. Both special interests served as a kind of coping response or adaptive strategy to the frenzied world outside. However, the special interests that served as an escape also made N5 more socially isolated. He stated that he did not want to bring others into his inner sanctum for fear they would tease him or divert his attention from the music or the television.

N5's experience of having a special interest was highly focused on the textural theme of coping. He utilized his interests as a way to develop his language and pattern his social interactions. Paradoxically, he used his special interests to isolate from others, thereby escaping the social demands placed upon him.

Individual Textural Description: A7

A7 is in his mid thirties and was diagnosed with Asperger's syndrome in adulthood. He currently lives with his sister and has returned to school to obtain an associate's degree. His special interests included cartoons, road signs, and trains. The textural themes that emerged for A7 were special interests providing strategies for coping, and as addictions or obsessions paired with a heightened sense of excitement. A7 also indicated he enjoys knowing that people consider him an expert on certain topics, although others have ridiculed him for his peculiar interests.

A7 began the interview with a discussion of his first special interest, Popeye. He indicated that most of his special interests followed a fairly predictable pattern. "There was right. There was wrong. Somebody was doing bad, out came the spinach. Popeye took care of the bad guy, he sang his song, iris [sic] out, the end." These predictable components of the cartoons offered A7 a sense of order in a chaotic world. A7 soon began to notice details in the film outside of the plot and characters that captured his interest. These esoteric aspects, such as scratches on the film, what year the cartoon was made, and who distributed it began to dominate his thoughts. He affirmed, ". . . it was the trademark, the music, the character design that fascinated me." He also described a few physical manifestations of his excitement. He indicated that he liked to blow the hair on his arms while watching television; he would also pace and wave his arms when he was younger.

A7 consistently referred to his special interests as obsessions. He stated that he experienced "tunnel vision" while engaging in his interests. He would often lose track of time. "I'll feel myself getting obsessed with stuff, and if I have that spell, if you will,

broken or disturbed in the wrong way or at the wrong time, I still become highly annoyed beyond all reason." A7's ability to focus on his interest for hours at a time can be seen as a direct response to his otherwise disjointed attention. He described himself as a "hyper-active child" most of the time, but he was capable of extended time periods in complete concentration; however, his special interests took precedence over all other activities. A7 stated that his interests became his "trademark" or the way in which others identified him:

Anyone who knew me from the first to the sixth grade would say, "Oh he is the cartoon kid." Ask anyone from the 7th to the 12th grade and they would say, "A7 is the guy who is into the Three Stooges and Laurel & Hardy." Ask anyone who has known me since then and they will say, "Oh yeah, he is the guy that is the rail fan or the train buff. Yeah, he was over at the railroad club. He was the vice president for awhile, he has got all those train books." So I become known for whatever I am obsessed with at the time.

A7 liked the notoriety brought on by his unique interests but he also realized it made him different from other children and caused him to be "socially isolated." He was personally offended if another child on the playground started singing the theme song to Popeye in the wrong way. He described scenarios where he would approach children on the playground that he felt were making a mockery of his hero. It would annoy him when kids sang a variation of the "Popeye the Sailor Man" song. To these children he would say, "I don't think Max Fleisher would appreciate you singing that." He further commented:

I would always try to defend my interest and I realize now how utterly bizarre that must have been . . . The fact that they were talking about this thing that I was so into, that I knew intimately. They might as well been saying something about my mother to me. I felt like I was defending myself.

A7's unusual response toward his peers did not make him popular. He believed that because he was not as socially connected to others, he used his special interests as a

way to be noticed and acknowledged by others as an expert. He affirmed, "I suppose there is a certain neediness because I'm not connected to the rest of the social world; maybe that I have to make myself and my interests known." A7's desire to be noticed created a strong connection to his special interests. His difficulties in the social realm made him uneasy but in the world he created, the world of special interests, he felt confident and knowledgeable as the expert.

Well I became absorbed in my special interests because I felt socially isolated not being able to understand the social aspects of things on the floor level, if you will, on the ground. But I became socially isolated from society because of my special interest. It is a circle almost. It works both ways. The more people thought I was weird, the more into it I became. The people that thought I was neat, that it was cool that I could name that obscure actor standing in the background, and I can still do that today, the more I enjoyed what I was doing. It is like being recognized for something that you are good at.

In the above quotation, A7 conveyed that his special interests created a double bind for him. The interests served as a bridge for him to connect with and relate to his peers. He felt recognized and admired by some of his classmates for his unique knowledge. Yet at the same time he would become "obsessed" by his interests, which would make him more socially isolated.

For A7, all three textural themes were present. His special interests served as a coping mechanism. In addition, he spoke of feeling obsessed by and addicted to his special interests, and he discussed his longing to be recognized and acknowledged as an expert.

The three textural descriptions brought to life describe the textural themes identified in this study.

Composite Textural Description

The composite textural description encompasses all the textural thematic aspects of the data. The question, *How does an adult with Asperger's syndrome experience having a special interest?* revealed three primary textural themes: 1) special interests were utilized as a coping mechanism; 2) special interests can become addictive; and 3) adults with Asperger's syndrome desire to be valued and respected via their special interest. These themes were a direct result of phenomenological reduction, revealing the composite picture, and allowing for a deeper understanding of the experience.

Coping, which permeated 10 of the 12 interviews, comprised four distinct aspects: 1) anesthetize or escape; 2) provide calming; 3) focus attention; and 4) maintain a sense of predictability by being object focused.

Research participants described the need to escape their stressful worlds where they often felt misunderstood. The social milieu was confusing and their difficulty reading nonverbal signs caused them to feel cast out by their peers. Special interests provided the research participants a way to insulate from the chaos they experienced in their environment. Some research participants described their special interests as a drug that could dull the pain they experienced while being in the neuro-typical world.

Ten of the 12 research participants stated they used their special interests as a way to "focus" or "anchor" their attention. Many indicated difficulty harnessing their attention outside of their special interests. The experience of "flipping" from one thing to the next, or feeling "scatter brained" was an element of this aspect of the investigated phenomenon. In response, the special interests provided a solution in that the adult with AS could become hyper-focused on a particular subject. Some participants described

engaging in their interests as “tunnel vision.” While this provided a solution to poor attention, it also proved problematic. Becoming hyper-focused created situations where the adult with Asperger's syndrome was unaware of other aspects in their environment that could be dangerous to themselves or others.

Engaging in special interests as a strategy to provide calming was another aspect of the textural theme of coping. Nine of the 12 research participants indicated they were in an almost constant state of anxiety due to the social and academic demands placed upon them. Their special interests created a sense of calm and peace they could not experience elsewhere.

For adults with Asperger's syndrome, creating predictability was another way to organize and cope in the world. Seven of the 12 research participants spoke of selecting special interests that were predictable. Their interests were typically based around objects such as stuffed animals, roads, or trains. If the interest was a game show or cartoon, the focus was not on the content of the program, such as a contestant on the *Price is Right*, or the cartoon character Popeye. Instead, the adult with AS was fascinated by a voice or the year a cartoon was distributed or made. The static, unchanging, predictable aspects of the special interests provided them with objects or aspects they could fixate upon and count on in a world that felt otherwise unmanageable.

The second textural theme cited by the research participants was described in terms of addiction. Five of the 12 participants stated they felt “addicted” to or “obsessed” with their special interests. Nine of the 12 stated being totally “immersed” while engaged in their interests. The participants felt “ruled by” their special interests and indicated that it “was the most important thing” in their lives. While engaging in their special interests,

some research participants indicated a heightened state of excitement manifested in physical responses, which included, “hand flapping, pacing, jumping up and down” and even a sexualized response characterized as an “intellectual orgasm.” One participant stated she could become so aroused by certain sounds that she could be “. . . tempted to have an affair.” Two of the 12 research participants indicated engaging in repetitive aspects of their special interests, either by watching certain parts of a video over and over, or listening to particular segments of music. The repetitive aspect was described as part of the addictive quality of engaging in their interests. “Watching it just once was never enough . . . the more I watched it the more I wanted to watch it.”

Another component of this theme was the research participants' reverence toward their interests. Interests were described as “sanctuaries,” “temples,” and “havens.” One participant stated he “thanks God” for giving him his special interests.

Research participants also drew parallels between the mind-altering effect of drugs and special interests. They indicated that their special interests stimulated mood altering responses. Words like “hypnotic” and “elixir” were used in reference to the transported feeling they had while participating in their special interests.

The final textural theme was that of being valued and respected. The special interest became the strategy that research participants employed to gain this respect. Developing encyclopedic information on specific topics made them experts in select subjects. Research participants realized that some people admired and respected their unique talents and detailed knowledge of their topics of choice, which reinforced their desire to accumulate more information. Some participants stated that their special interests were their “trademarks.”

Structural Themes

The seven universal structures include relationship to self, relationship to others, bodyhood, temporality, spatiality, causality, and materiality. An overview of verbatim material pointing toward the structural aspects of the experience is presented. To preserve a sense of flow, research participants are not identified in the overview.

Relationship to Self

The primary researcher identified two elements that appeared for the majority of research participants: focus and calming. The participants indicated difficulty harnessing their attention and controlling their anxiety when interacting in the neuro-typical world. To help them cope, special interests were utilized to heighten their attention and settle their nerves.

In a world where research participants felt adrift, special interests were used to “delve,” “ground,” or “anchor,” which helped focus attention. Aspects of spatiality arose in this theme and are discussed later in this section.

Focus.

“I think my special interest has given me a focus. I’d be even more unfocused in my life if it were not for special interests and I thank God for them. If I didn’t have a special interest I’d be walking around endlessly.” “If it wasn’t for my special interests, then I would just know a broad amount of attention to everything and then I’d be way more scattered-brained than I already am.” “I was a little bit scattered and I had a little problem sometimes always paying attention it was just more like this overzealous attention to detail.” “I will listen to Beethoven and something like string concertos or something like that, string pieces and I’ll be writing and I’ll just be able to keep writing

because it helps my thought flow.” “We could see something that would be diverting and that we could watch and have a focus on.” “So we can focus on little things like cars and bikes without getting into a higher level of thinking.”

Calming.

The research participants indicated they would often feel anxious and overwhelmed, and sought ways to bring a sense of peace into their lives. Special interests were utilized as coping strategies. When listening to music “. . . my mind goes limp and just relaxes. It is not like I have this sensation of all of a sudden having to move up and around or something like that. It just helps me calm down a little bit and relax.” “. . . a way to relax.” “Westerns were calm and quiet . . . they made sense . . . you can escape there and you can rest in the West. There is no noise, there is no traffic, there are no people pounding on your door.” These examples demonstrated the use of music, westerns, and bicycles as coping strategies. Each one of these special interests offered a means by which the research participant could calm him or herself. The calming elements and focus their special interests provided helped the research participants feel more comfortable with themselves.

Relationship to Others.

The analysis of relationship to others yielded the following three elements: 1) Special interests established a bridge to social connection by being the expert; 2) “Data dump,” the tendency to repel others by revealing too much about their special interest, and 3) Research participants created a group identity to normalize their eccentricities and identify with others like themselves.

Special interests established a bridge to social connection by being the expert.

The special interest facilitated connection to others by providing an opportunity to become an expert. “We can become our own expert and so since the world gives some value to so-called experts in different fields, you can become an expert in this or that, people put their thumbs up and say, “Wow!” “I enjoyed being in the kitchen . . . learning things from [others] that I’ve enhanced upon and made better; things that they would make, they would have been known for, but now I’m known even better.” “I have a tape collection that marvels most people.” Ten of the 12 research participants indicated that their special interests created a bridge to social connection. Becoming experts on particular topics set them apart and garnered attention from others. Their special interests made them unique and special; simultaneously, it allowed them to share their knowledge and be resources to people in their lives.

“Data dump,” the tendency to repel others by revealing too much about the special interest.

“Going into a monologue about the bicycle.” “I was able to talk on and on and on about it.” “Just telling the whole thing, that I have this knowledge and you don’t. I know more than you do and I’m going to tell you all about it . . . while you sit here in rapt attention. You are going to pay attention to me.” “They would have a certain threshold . . . I would always have more to say whether it is a close friend or a distant person.” “I could just go on and on about certain things, certain topics.” “I’d bring up all these subjects or something like that and then I discovered I’m turning gals off because it’s like they are not going to want to deal with a guy that does all the talking.” “I can go on and on and on about it.” “I would talk about the Three Stooges for hours on end.”

The *data dump* or the tendency to go on and on about special topics was a common theme. The special interest was utilized as a bridge to connect with others, but once the adult with AS began to speak about their subjects of interest, they were often unable to stop. The unfortunate result, as many of the research participants noted, was a decrease in their ability to stay connected with others who quickly became overwhelmed and put off by the influx of information being thrust upon them.

Research participants created a group identity to normalize their eccentricities and identify with others like themselves.

“An Asperger’s mind.” “So if we have a special interest.” “I’m becoming Aspergery.” “Not understanding the social milieu and understanding the way people interconnect contributed to me or any Aspy becoming further obsessed.” “By we, it’s the royal we, if you will, and just referring to an Aspy in general, I’m assuming other Aspy’s have experienced the same thing I have with their special interests.” “I tried not to get all Aspergery and sweaty palmed and excited because people think it’s nuts.” “I will set time aside to be Aspergery.”

Many of the research participants utilized the terms “Aspy,” “Aspergery” or the pronoun “we” when referring to their own experience regarding special interests. The use of the “royal we” served two purposes. First, in the examples, the research participants revealed some of their eccentric behaviors associated with Asperger’s syndrome. Attributing these unusual behaviors as typical reactions served to normalize the unusual behavior. The second reason for using the “royal we” revealed the need to be part of a social group. Most of the research participants report having never belonged to a group or were accepted socially. Once they received the diagnosis of Asperger’s syndrome, they

felt they belonged; their unusual behaviors were normalized and they could celebrate their uniqueness instead of feeling ashamed. Underlying this structural element is the assumption that people with AS believe all people diagnosed with Asperger's syndrome experience their special interests similarly. This may explain the research participants' tendency to generalize or project their individual responses onto those around them.

Bodyhood

For the adult with AS, the universal structure of bodyhood is characterized by both a heightened sense of physical excitement, which manifests as jumping and pacing, and an inability to locate their bodies in space or feeling "floaty." One participant indicated that when riding her bicycle she became more physically connected to the world. Another research participant experienced his special interests as a place to put his mind, inferring that without the special interest he would be lost or "scatter-brained." This structural element revealed aspects of stimulation, disconnection, and dislocation with the body.

For the adult with AS, special interests stir a significant sense of excitement and body awareness, as indicated by the following research participants' statements: ". . . jumping up and down when an exciting moment happened." "I would start pacing when something exciting happened." "I felt floaty. I used to jump off roofs and out of trees to feel the world underneath me; you know, a physical connection." "On bikes you could go down hills bump, bump, bump; there was no doubt that you were connected. I could feel my weight in space, my body made sense. On a bike I felt connected." "it gives me something to put my mind on." "Without my special interest, I would be more scattered brained than I already am."

Temporality

Research participants described the time they spent engaging in their special interests as passing quickly. One individual stated the world would open up and he would escape for hours. Some participants affirmed they could talk about their special interests for “hours;” similarly, time was “filled up” and “flew by.” One research participant indicated he “set time aside” to engage in his interests.

“I will set time aside to be Aspergery;” “I could easily get lost in the interest;” “A whole world of diversion opens up on that page and I could be gone for hours;” “. . . when it [special interest] fills all your time. You don’t realize it. It’s like . . . I’ve been on this thing for eight hours? I mean eight hours straight!;” “I would talk about the Three Stooges for hours on end;” “ I can remember the feeling as though those six hours went by just like that because I was so enthralled in it; time just flew by.” For the adult with AS, engaging in special interests resulted in time’s rapid movement.

Spatiality

In relation to special interests, space was described as bottomless. The special interest could be something one could become “lost in” or “delve into.” Special interests were something one could “put their minds on” to avoid feeling “scattered.” Participants felt a sense of grounding, connection, and being anchored while engaging in their interests. Special interests were also used to connect to the physical world to combat the feelings of weightlessness or “floating.” One research participant stated that his special interest helped him avoid moving through space in an endless fashion. The special interest helped him to narrow his focus and concentrate. Also, special interests were described as expansive in that new worlds could be opened and revealed.

Some participants utilized the term “tunnel vision” to describe a laser-like focus while engaging in their special interests. This revealed a narrowing and lengthening of space, as described in the following statements. “So if we have a special interest it gives us something that’s familiar to us and then we can delve into;” “it gives me something to put my mind on;” “I felt floaty, I used to jump off roofs and out of trees to feel the world underneath me, you know a physical connection. On bikes you could go down hills bump, bump, bump; there was no doubt that you were connected. I could feel my weight in space, my body made sense. On a bike I felt connected;” “If I didn’t have a special interest I’d be walking around endlessly;” “A whole world of diversion opens up;” “I remember it got me extremely tunnel-visioned; like my whole day was focused around the game shows;” “Tunnel vision; I’ll feel myself getting obsessed with stuff.”

Causality

This structure refers to cause and effect relationships in the world. The structural element of causality possessed two elements: 1) the double bind, and 2) choosing predictable objects instead of unpredictable people. The double bind refers to the inherent paradox associated with special interests.

The double bind.

The interests, which were selected as a way to opt out of the social milieu, also provided an opportunity for social connection. Yet the interests became so absorbing they caused the individual with AS to be more socially isolated.

Well I became absorbed in my special interest because I felt socially isolated, not being able to understand the social aspects of things on the floor level, if you will, on the ground. But I became isolated from society because of my special interest. It’s a circle almost, as it works both ways. And you don’t realize it is happening. I look back and by fifth or sixth grade I was not doing school work. I was socially isolated because of my cartoon thing.

Choosing predictable objects instead of unpredictable people.

The participants discussed selecting special interests that were predictable and unchanging. This could be viewed as a direct cause-and-effect response. The social world and people in it are inherently unpredictable, causing the adult with AS to experience anxiety. Therefore, to ease the heightened state of anxiousness the individual chooses to spend his or her time focused on predictable objects or unchanging aspects of the special interest:

Like a kid with a teddy bear, I was with my bike. It was my special friend, I liked to read about bikes, I liked to talk about tires, I liked to watch bike races, there wasn't anything about the history of bikes, the color of bikes, or the bike racers, the gears, the whole thing was enticing to me . . . more important to me than a human.

I was in a comfort zone; I wasn't around like the big social world because I would feel very alone because . . . [stuffed animals] was my safety world because I understood what was going on, that was my fun time, my playtime.

The following statements further reflect this concept, "It was satisfying because you could start to predict how things were gonna go, so that gave me joy because I don't like surprises. So I would get excited because I knew how [it] was going to end;" "I was more interested in the bicycle than the person on it;" "The stars and planets remain the same always and the information about them remains the same and it was predictable, what they would do or not do and how they look;" "There was a certain formality about them and they were extremely predictable . . . the music was the same every single time . . . and that was fascinating to me;" "Things that were exciting to me were the predictable things, so like when the game show opened that was exciting to me even though I knew what the opening was going to be like because it is the same everyday."

For these research participants, the element of causality was paradoxical.

Engaging in special interests allowed them to feel more comfortable socially, yet at the same time, resulted in their social withdrawal.

Materiality

The primary researcher did not identify data connected to materiality, most likely due to the concrete nature of the AS population's thought and speech process (Attwood, 2003). The universal structure of materiality is usually revealed in metaphoric language. Those with AS, however, typically avoid using esoteric aspects of language that include idioms and imagery.

Individual Structural Description: L11

The individual structural descriptions serve to illuminate the essences of the structural elements identified in the data. L11 is a woman in her mid forties and the mother of three. She has been married for more than 15 years and is a professor of linguistics. She received her diagnosis of AS in childhood. Her special interests included bicycles, westerns, horses, and language.

The universal structures most evident in her interview were relationship to self and other, bodyhood, and causality. L11 stated she had a close relationship with her father due to the similarities in their character. They were both drawn to activities that are predictable. She stated that she was not interested in other children, but enjoyed engaging in her special interests instead. L11 described herself as obsessive and "like an addict" when it came to certain compulsions.

Bodyhood was another element that appeared in L11's interview. She indicated that riding her bicycle and her horse helped her to connect with her body. As a child, she

also craved “crunchy” textures, which demonstrated the need to feel and literally chew on objects in her environment.

The structural themes present for L11 were infused with feelings of anxiety in response to the outside world. She indicated that she never knew when people were making fun of her and often felt paranoid when she spent time among her peers. This fact heightened her attraction to objects rather than people. Her tendency to be object focused was tied to the idea that objects provided predictability. Predictability created a sense of calm and satisfaction she did not find in the outside world. Her need to decrease her anxiety was a causal factor in her drive to structure her environment via her special interests.

Relationship to self.

L11 described herself as “obsessive compulsive.” She indicated that she felt the need to count in order to maintain a sense of composure. “Things had to be symmetrical. I would walk over 10 steps and then I had to jump. I could not walk anymore steps. I did things in whatever my number of the day was, but on my bike it was always 10 miles.” She affirmed that if she did not give into her compulsions “. . . the anxiety [was] just overwhelming.” She characterized herself as an “addict” when it came to her need to count, “It brought me satisfaction . . . I just gave in to it.”

Relationship to others.

L11's first special interest was bicycles. The selection of this interest was influenced by her father. She indicated that she and her father shared similar emotional traits and were both interested in things of a “concrete” nature.

My dad is an engineer and I think part of the reason he gave into my obsession with bikes is because he liked putting them together and he liked talking about

why wheels go around. He could talk scientific lingo to me around the bicycle. If it was a doll, he would have looked at me like I was insane. But something like the bike that he can actually tinker with, fix up, and be mechanical with, we could have conversations around that. "How's your air pressure, how's your tire pressure." That would lead to discussions like: "Do you know why wheels work? Do you know why they stay on the ground? Do you know why poppers work?" [He] was definitely mad about physics.

L11's father indulged her interest in bikes. She stated, "My dad was a frugal Scotsman but he could never say no to a bicycle, and I think that's because he also enjoys anything within the realm of physics." The connection between L11 and her father was strong due to the fact that she ". . . never related to kids my own age." She stated that her bicycles were ". . . more important to her than a human." Her father was the gateway to her special interests and she described her relationship to him as "tight." These statements incorporate two structural elements, spatiality and relationship to others. L11 attributed their close connection to the fact that their thought processes were "virtually identical."

Bodyhood.

In the following discussion, the concepts of weightlessness and grounding are touched upon. The primary researcher deemed that the research participant was predominantly referring to the experience that is best captured under the structural category of bodyhood.

L11 described that while she was not on her bike she often felt "floaty" or disconnected from her body and the ground. Riding her bike provided her with a feeling of connectedness she did not usually experience. She stated that her special interest in bikes was her way of ". . . trying to connect with the universe felt floaty . . . On bikes you could go down hills, bump, bump, bump; there was no doubt you could feel your weight in space." She indicated her special interest in bicycles served multiple purposes.

It allowed her to develop a “tight” relationship with her father and connected her mind to her body, thereby grounding her to the universe. She also noted an “obsessive interest in things that were chewy and crunchy.” She stated, “I remember eating tin foil, and wanting to chew on nail files and match books and things like that. That upset my mother because [she had to] take me to the ER twice because I kept eating moth balls.” L11 appeared to be under-reactive to her environment in that she sought deep, physical, pressure from her bike and from horse rides in order to feel connected to her body, and craved oral feedback from inedible objects.

Causality.

Predictability was a dominating theme for L11. She cited that her interest in westerns was largely due to the predictable plots. She stated, “Part of what was satisfying . . . you could start to predict how . . . these shows were all quite predictable . . . You could predict how the things were going to go so that gave me joy because I don’t like surprises.” Her need to order her world caused her to select activities that followed a set pattern. She affirmed: “Human behavior never made . . . and still doesn’t make any sense to me. I have a hard time thinking it is random.”

Her interest in horses is another example of the need for predictability. She stated:

And so when I go to the barn, my horse does not talk. My horse is always predictable: “Feed me and I will love you. When I raise my right front leg it means I want a treat;” so we understand each other’s language.

Conversely, interactions with humans are often confusing for L11. She stated about her horse:

[I don’t have to] guess what he is thinking. I know what he is thinking. He does not try to hide or be polite, be kind or gracious or fool me or get me into a situation where he would abuse me. He is very honest.

L11 affirmed that the horse was not going to fool her or abuse her. The horse “is what he is.” The predictability inherent in that relationship brings L11 a sense of peace and comfort.

When I am in a bad mood this horse is calm and when I am in a hyped mood he is hyped. When I want to run, he runs. When I want to walk, he walks. We are completely in tune with each other and no human can give me that.

When interacting with humans, L11 revealed that she plans every aspect of her own interactions. She acknowledged, “Before I go out I think about what I am going to say, what I am going to wear, what I am going to eat, what we are going to talk about, the direction the night’s going to take.” For L11, human interaction was anxiety provoking and confusing. Her angst caused a need to plan and control her environment. L11 was able to successfully keep her anxiety at bay by engaging in highly predictable activities.

The structural elements of relationship to self and others, bodyhood, and causality were present for L11. She experienced people as unpredictable, which provoked a stressful response and way of being in the world. Also, she reported feeling disconnected from her body, and that only when riding her bike or a horse could she feel her weight in space. Her special interests helped her establish a common bond with her father, manage her angst, and feel grounded.

Structural Description: M8

M8 is a Caucasian male in his early forties and is married with no children. He earned a master’s degree in computer engineering. M8 is of European decent and currently resides in England. He received his diagnosis in late adulthood. His special interests include croquet and watching the television series *Fawlty Towers*. The structural

elements gleaned from M8's interview were relationship to self and other, temporality and causality.

Relationship to self.

M8, described himself as “flipping” from one thing to the next. He characterized himself as highly distractible. However, his special interests provided him with a sense of calm and a heightened ability to focus. In the quote below, M8 stated that he did not need to “exert” himself while watching his favorite videos. Therefore, one can deduce that much of the time the simple act of concentrating and focusing required a great deal of effort on his part. Engaging in his special interests provided a time for self-soothing and escape from the exhaustion he experienced being in the world.

I do have difficulty focusing. I'll flip from different things. One minute, instead of just finishing and concentrating on that, I will flip to something else. I think that's because part of the time I have difficulty maintaining my concentration. . . . I can sit down in front of the television and I can watch it all day because I can become engrossed in it and I don't get distracted. It's a really calming experience for me. When I watch something like *Fawlty Towers*, which is basic comedy, I know what is going to happen. I don't have to exert myself mentally or in any major way. It's easy to watch, it's incredibly relaxing, it's calming for me to watch it . . . I know exactly what's going to happen.

Relationship to other.

M8's relationship with others yielded multiple themes. He indicated a desire to be respected and liked, and he utilized his special interests and ability to memorize massive amounts of statistical data as a way to impress people. However, he was also aware of his tendency to over elaborate about his special topics, which could repel the very individuals he intended to impress. He conveyed that people thought of him as eccentric and sometimes strange. His identification with the AS population helped him connect with others who shared a unique set of traits, while at the same time normalized the unusual

behaviors he exhibited. The following quote elucidated this concept of group identification:

When I quoted you the example of the Ipswich football team from 1978 finals, the guy was quite astounded that I could [remember] that. When I met the lady in the estate agency, I remembered what her daughter did, and she was amazed by that. I think you have to be a little careful of those *Fawlty Towers*, it's quite a sort of wacky type of thing and I think even you've got to be careful and perhaps I have a tendency to sort of go on about too much. Off course the problem with that is, is that's the sort of downside in Asperger's--that people think you are a bit odd sometimes.

M8 conveyed that people consider individuals with Asperger's as strange.

Aspects of group identification are apparent in his frequent use of the phrase "people with Asperger's" and "we" when referring to his personal experiences. M8 acknowledged a desire to be accepted, respected and popular. He indicated a time where he was bullied by others at work. Overall, M8 conveyed that socializing and being with people has been an arduous task for him due to his eccentric nature.

I think as somebody with Asperger's syndrome you can't just adjust to the fact that you are different because there's things about you that people find strange . . . so you are always self conscious about things like most people with Asperger's, you worry about being liked and it is a concern sometimes because you want to be liked, you want to be popular. I wouldn't say I am unpopular or anything like that but like most people with Asperger's it's not easy for me to go out and socialize very easily or be the sort of "belle of the ball." So, I supposed maybe I will say that we want to be respected. There are sometimes I've had in my work career one or two instances where I suppose I was bullied. People show the lack of respect towards me on a personal level that is never pleasant.

Under the structural theme of relationship to others, M8 revealed that he often misses the social nuances that take place between people, especially while watching a movie. He described his need to watch a movie more than once to understand it. In conjunction with the multiple viewings of a movie, M8 acknowledged that he needed the

help of another individual to point out the relational subtext of the plot. In the following quote he referred to aspects of the social world as “hidden” or obscured from his view:

I love watching favorite films again. My wife doesn't. My wife will watch one film and that's it. It is very, very rare for her to watch a film again. Every time I watch a film or one of the episodes I take something new from it. When I watch the films with my wife for the first time, often at the end of it, she will explain things to me particularly the nuances and emotional aspects between actors that I have missed. She will pick up on the things unwritten, the hidden agenda. Those are things I won't pick up on. She will explain it to me and then I will watch the film again and I will say, “Oh, I recognize that, I understand it now.” So I can take an enormous amount from it.

This “hidden” element described by M8 could also be considered under the structural category of spatiality. However, the primary researcher regarded this aspect as a larger issue within the context of relationship to other. M8 indicated there are large components of human relationships he cannot independently recognize or comprehend. He used his wife as a translator and guide when trying to decode the social realm.

For M8, relationship to others revealed multiple themes. He conveyed a strong desire to be respected and liked by people. He utilized his special interests and ability to memorize inane facts as a way to impress others. However, he was also aware that he tended to over elaborate about his select topics, which repelled the very people he intended to impress. He stated that people thought of him as eccentric and sometimes strange. M8 identified with the AS population through his usage of “we” and “people with Asperger's” when conveying his individual experience. This helped M8 to connect with others who shared a unique set of traits, and normalized the unusual behaviors he tended to exhibit. Lastly, M8 affirmed that he does not always comprehend the nuances of interpersonal interactions.

Temporality.

While interviewing M8, the primary researcher became aware of his tendency to attach a date, time, and age to the experiences he shared.

In 1971 when I was 10 years old, I remembered glimpses on the television of the first series that summer against India but only vaguely. And then it was the following summer, 1972, that I really got engrossed in my first series, which was against Australia which is like the home of the croquet series for England. It was 1972 and I followed that series insidiously. There were five tests and the England team would announce those five tests and I think if you were to say to me, if I was to put my thinking cap on, I could remember the teams for each of those 5 games. I have another example, I can remember about 17 years ago . . .

It appeared that M8 had attempted to identify, specify, capture, and contain time; he tried to quantify every aspect of his experience. This can be seen as another attempt to order, control, and contain circumstances in his life.

Causality.

M8 indicated that the social world proved to be a mystery to him. He described aspects of human interaction as “hidden” from his view. If one does not understand the way in which people interact, or they miss the nuances of human connections, the world becomes a confusing place. Therefore, it is no coincidence that M8, like many of the other research participants, selected special interests that are highly predictable. M8 indicated that he could relax and unwind while watching *Fawlty Towers* because he knew what was going to happen. He did not have to exert himself to unravel and comprehend the plot. Choosing predictable activities can be seen as a direct response to living in an unpredictable and confusing world. M8 stated:

When I watch something like *Fawlty Towers*, which is basic comedy, I know what is going to happen. I don't have to exert myself mentally or in any major way. It's easy to watch, it's incredibly relaxing, it's calming for me to watch it . . . I know exactly what's going to happen.

The structural elements gleaned from M8's interview were relationship to self and others, temporality, and causality. M8 described himself as a person who "flips" from one activity to another. He utilized his special interests as a way to improve his attention span and sharpen his focus. His special interests provided a way to connect with others, especially people diagnosed with AS, whom he described as sharing many of his eccentric traits. While M8 admitted that the social world was a mystery to him, he used his relationship with his wife to help him unlock the hidden aspects of social interactions. M8's description of his experience was laden with references to time. He frequently contextualized an anecdote with a date, time, and age. "In 1971 when I was 10 years old," was one such example. For M8, time appeared to be a focal part of his experience and possibly another way to quantify, and thereby control, one aspect of his life.

The structural theme of causality was identified in M8's interview. Similar to L11, M8 chose to engage in highly predictable activities. This can be viewed as a direct cause and effect response. The cause: Living in an unpredictable world provoked anxiety. The effect: wanting to relieve the anxiety and return to a state of homeostasis. As a result, M8, chose to spend his time engaged in special interests that were predictable and easily controlled. This decreased his anxiety and allowed him to relax and regain his composure.

Structural Description: A4

A4 is a single male in his mid thirties. He lives independently in a condominium located within walking distance to his work and parents. A4 does not drive. He is in a long-term relationship with a woman he has been dating for the past decade. A4 earned his associate's degree in the field of culinary arts and works as the head chef at a local

restaurant. He is active in his synagogue and has been acknowledged publicly for his philanthropic service to the community.

A4 was diagnosed with Asperger's syndrome in his teenage years. He received special education services throughout his educational career. His special interests included *The Grand Ole Opry*, bowling, cooking, maintaining a monthly family newsletter that goes out to 150 of his relatives, volunteering at his synagogue, collecting autographs of television actors, collecting synopsis books from television programs, and watching game shows, soap operas, and classic television programs such as *The Waltons* and *My Three Sons*.

The structural elements revealed in A4's interview were relationship to self and others, temporality, and causality. Some of the structural themes overlapped; they are handled and discussed as they occur within a particular verbatim quotation.

Relationship to self.

A4 indicated that he always had difficulty with his inattention. He acknowledged having a "short" attention span, and stated that his memory has caused problems for him. A4 utilized his special interests to combat the challenges that his memory and inattention caused him. He indicated that it was easier for him to concentrate when he engaged in multiple activities. A4 kept records of statistics and alphabetized his collections so he could easily retrieve the data he needed if his memory "failed" him. He stated, "I'm not the type of person that actually sits for very long. I have a very short attention span in terms of sitting. I can't do one thing very long; I have to do 20 things." A4 believed that he was able to improve his focus by engaging in multiple activities or moving from one thing to the next. His special interests provided him with a sense of purpose and an ability

to compensate for his issues with attention. This can be viewed as a coping strategy. A4, in response to feeling unfocused, found a way to harness his energy and accomplish his goals. He indicated, "People know I can put my mind to do something and I will get it done. It may take longer than most, just because of my short attention span, but I will get it done."

These examples addressed A4's self determination and perseverance in the face of adversity. The examples also pointed to several other structural elements such as spatiality, causality, relationship to other, and temporality. A4 placed his mind on something (spatiality,) which improved his focus (causality). He recognized it might take him longer (temporality) than other people (relationship to other) to complete the task, but he persevered to achieve the desired outcome (relationship to self.) A4 revealed an ability to find solutions for his tendency to lose his focus. He admitted that his ". . . mind tends to wander; I get bored very easily with things." Therefore he does ". . . twenty things while I am listening at different times. I will be doing one thing, then I will do another thing, then I will do another thing, then I will do another thing and go back to that thing." By diversifying his attention he says he improved his ability to focus.

A4 also indicated that he sometimes has difficulty recalling information. One aspect of his special interests is to collect statistical data, which he can utilize if his memory fails him. He stated:

"[I collect statistics.] That way my memory works or doesn't work in most cases because sometimes my memory, and I am old enough to say, that sometimes my memory doesn't serve as well as it should. So, here I have got all these recordings down of all the shows, so it helps my memory as well, so I don't have to guess on anything. If my memory fails me I can just go back and look, and sure enough I can remind myself."

A4 demonstrated capacities to cope and persevere. He utilized his special interests to overcome his challenges with attention and lack of focus in addition to his difficulties regarding his memory. He found that by spreading his attention among multiple tasks he could actually improve his focus. His interests in collecting statistics, keeping records, and categorizing information helps him compensate for a memory that sometimes fails him. A4's ability to find solutions revealed a resiliency and determination of character.

Relationship to others.

Under the structural element of relationship to other, three themes were gleaned from the data: 1) Special interests made him feel useful to others; 2) Being the best at something created a sense of importance; and 3) The special interest provided a connection to other people.

1) Special interests made him feel useful to others. A4 indicated that it was important to him to be viewed as a person others could go to if they needed information. He utilized his knowledge and expertise in his area of interest to assist people, which made him feel valuable and provided an opportunity to be acknowledged. He stated: "If somebody asks me a question, I can almost go back and look it up and have the answer for them almost instantly." He continued this sentiment by adding, "If someone asks, "When did so and so make their debut?" I can go just look it up and there it is in my records." While he acknowledged that some people might think his efforts are "meaningless and a lot of work," he feels that it is "worth every effort." Feeling helpful was important for A4. He spent copious amount of time gathering data in order to facilitate a sense of usefulness.

2) Being the best at something created a sense of importance. A4 revealed that he enjoyed cooking with his family members. Once he mastered a recipe, he improved upon the process and made it better. One example he cited was his grandmother's chocolate chip cookie recipe. He stated:

I've enhanced upon and made better things than they would make, that they would have been known for but now maybe I am known better.

. . . My grandmother used to be known for her chocolate chip cookies and now my cookies have become United States famous.

The preceding quote conveyed a sense of pride and accomplishment. Being known by others appeared to be vital for A4. In addition to being famous for his accomplishments, A4, revealed a sense of competition with others. He stated, "Well, I have an autograph book of pictures of me with other people that will just probably rival anybody's in all entertainment forms." On one hand, A4 revealed a need to be useful to others. He revealed a desire to be seen as both a resource for information and to be famous for his cooking skills. His expertise in certain areas elevated his status and provided an opportunity to showcase his abilities as someone who is "United States famous." A4 also saw himself as a person who could compete with others and outperform them when it came to certain aspects of his special interests.

3) The special interest provided a connection to other people. Connection to others was important to A4. He indicated that his special interest in country music was his gateway to friendships.

Most of my friends are country music related. They are like me; we like the music but we like to meet the artists and become real good friends . . . 99% of my friend base is through country music; through our interest.

In addition to maintaining connection with others through his musical interests, A4 also valued his relationship with family. He created and authored a monthly newsletter via email. The monthly letter, sent out to 150 of his relatives, acknowledged birthdays, anniversaries, birth announcements, deaths, and other noteworthy events in the lives of his relatives. A4 indicated that the support and love of his family has helped him to overcome his trials and tribulations. He stated:

Everybody knows how important family is to me . . . It just shows you that no matter how things get, family can always hold things together . . . just keep a little faith in your family and you can get through almost anything.

A4 recognized that some people do not have strong familial bonds. His desire to create a close-knit family unit inspired him to start the newsletter. He affirmed:

All families are not close and I think our immediate has been and I think that really plays a part in it, when your family is close like that, then you feel more togetherness and more in common things such as in my case, cooking and the newsletter.

A4 emphasized the words “close” and “togetherness,” which addressed the structural element of spatiality in that he wanted to eliminate or decrease the space between himself and his family members by drawing them close.

A4 utilized his special interests as a way to make himself useful to others, elevate his status, and connect to his family, whom he believed could help him overcome any challenges.

Temporality

The concept of time was predominant in A4's interview. The following quote revealed A4's tendency to quantify all aspects of his experience.

I started in school, in my earlier remembrance, back around '82 or '83, somewhere in that range of time . . . we went, that very first year and 21 years later, we have been going ever since. Well, the *Grand Ole Opry* is the longest

running radio show in American history; it is in its 82nd year. It just celebrated 83 years on its birthday. I go down to Nashville every year and the past 15 years for their birthday celebration in October.

When introducing a new subject, A4 referenced his age, the approximate year the experience took place, and how many years he engaged in a certain activity. The need to quantify his experience can be seen as a desire to order, control, and predict the world around him. This theory also can be applied to A4's acknowledged "madness" with categorizing, listing, and alphabetizing. The massive amounts of time he spent making lists of data points to yearning for order.

I have different boards where the tapes fit in, tape boards, and each group has a separate board. There is a board that has all the people who are *Opry* members for instance, the *Grand Ole Opry* in Nashville. There is a board that has all the members who are members; there is one where it has all the people who have performed at the *Grand Ole Opry* for the entire year; there is another board that has all the country music artists that are not members of the *Opry*; there is another one that has artists from the '50s and '60s, another board which has artists from the '70s; then stuff that is more current like '90s and beyond. Everything is categorized . . . I [have collected] different forms of music, but my madness has it all where it is all categorized.

A causal connection can be made between A4's fixation on time and categorizing to his feelings of being overwhelmed by the unpredictable nature of the world. The more out of control and anxious he became, the more he was drawn to activities that were highly predictable, easy to quantify, and therefore manageable. Ironically, A4 admitted to not understanding numbers, but affirmed the fact that he loved statistics. His interests in creating lists related to aspects of frequency and amount. He stated:

I love statistics. Statistics are figures. I don't understand numbers per se in business. Business I have no clue to numbers; but when it comes to things I really like, the idea of saying, "Oh, we have seen this one many times" or, "This has performed this many times." It just fascinates me to know all that information . . . I just enjoy doing it.

For A4, specifying and quantifying time was paramount. His apparent need to measure all aspects of his experience can be viewed as an attempt to manage and make sense of a chaotic world.

Causality

A4 described the need to escape from the frenetic aspects of his environment. He utilized his interest in television as a way to leave behind the confusion he experienced. He stated, "It is just an escape really into another world. You are watching these characters and it is just a fun escape." When life became too overwhelming, he sought a sense of peace and calm in the predictable plots of his favorite television shows. He acknowledged:

Things can be going just horrible, you're so upset and you come home and you put your program on and you just forget about all that. You can forget about anything else and you are just so engrossed in that show that that's all that matters. I mean sure you are not going to forget what happened, but it's going to give you that time, and I don't know if you want to say a cool down period necessarily; but it is just a time to escape from anything else that matters and to be drawn into that world of characters and those actors that they are putting across the screen.

These examples can be viewed through the structural lens of causality. A4's special interests provided a way for him to leave his outside world, the cause of his anxiety behind, and travel to a world that made sense to him. This in turn yielded the sense of relief and calming he craved.

The structural elements revealed in A4's interview were relationship to self and others, temporality, and causality. Relationship to self revealed that A4 had difficulty with attention and memory. He utilized his special interests as a way to focus his attention. His proclivity toward making lists and recording statistics helped him to

compensate for his challenges with memorization. A4 demonstrated an ability to persevere and overcome his disabilities in order to reach his goals.

Under the structure relationship to others, the primary researcher identified three components: 1) Special interests made him feel useful to others; 2) Being the best at something created a sense of importance; and 3) The special interest provided a connection to other people. The temporal elements revealed that A4 possessed a strong desire to order and control his world by quantifying all aspects of his experience.

Lastly, the theme of causality showed that A4 employed his special interests as a way to escape the chaos of his environment. Watching his television program was a time for him to relax and cool down, which allowed him the opportunity to regain a sense of composure and peace.

Composite Structural Description

The purpose of the universal structures is to unearth the essences that lay within the textural data. Consider the analogy of a shirt; the structural themes represent the parts of the shirt: the collar, sleeves, cuffs, and buttons. The textural themes pertain to how the shirt feels. Is it silky, scratchy, smooth, or shiny? The textures exist to illuminate the aspects of experience that are contained within and between the structural elements and to explicate how a particular experience is formed.

In the Transcendental Phenomenological model, the process of identifying the universal structures is called imaginative variation. Kurek-Ovshinsky (2002) compared this process to a kaleidoscope:

. . . the brightly colored fragments of glass within the tube of a kaleidoscope serve to filter, mirror, and reflect the changing patterns of individual experience. The variations overlap, interface, cross-over and even obstruct each other as the essences of the experience reveal themselves. (p. 120)

Relationship to self.

Many structural themes were uncovered regarding the special interests of adults diagnosed with AS. Research participants described difficulties with attention and focus. They reported feeling like their awareness was always “flipping” from one thing to the next. It was difficult for them to concentrate on one activity or complete a task. However, when engaging in their special interests, they could harness their attention, which brought a sense of relief and calm. The word “anchor” was used to describe how the special interest helped the adult with AS ground their energy and focus their attention. This was also an example of how the structural elements “overlapped” and “interfaced” with each other. Using the word “anchor” to describe the special interests revealed aspects of both spatiality and relationship to self. Participants indicated feeling adrift and disconnected to the flow of life due to their inability to attend; these aspects all pointed to the structure of space. Yet they also spoke to the core components of relationship to self. One participant stated he felt as if his brains were “scattered” and he was walking around “endlessly” without a sense of purpose. Special interests facilitated a sense of “flow” and provided an activity that adults with AS could “put” their “minds on.”

The research participants experienced themselves as highly distractible and sought strategies to compensate for this perceived weakness. The anxiety they experienced due to their lack of focus permeated all the interviews. The participants were all quite aware of feeling uncomfortable in the *neurotypical* world. Engaging in special interests provided a way to cope, in that the activity provided a sense of calming. Here again, the overlapping of structures was apparent. The primary researcher identified four structural elements interconnected with the aspects of calming or self soothing. The

participants, aware of their overriding anxiety (relationship to self) sought to find an escape (causality) or a place they could “cool down” (materiality), “get lost” (spatiality) or “allow [the] mind to go limp” (bodyhood).

Relationship to others.

Analysis of this structure was often confusing. Three primary themes were identified: 1) Special interests established a bridge to social connection by being the expert; 2) Data dump, the tendency to repel others by revealing too much about their special interests; and 3) Group identity formed to normalize eccentricities and identify with others.

Research participants revealed that the social world and its rules were “hidden” from their view. They found interacting with others a risky endeavor. Many of the participants used their special interests to connect and reach out, but because of their tendencies to “go on and on and on” about their special topics, they repelled the very people they intended to impress. This left them feeling isolated and alienated, and longing to find a place where they could belong and be accepted.

Research participants frequently generalized their personal experiences. When describing their individual response to a situation, they stated, “People with Asperger’s syndrome . . . ;” or “Aspies tend to . . . ;” “People with AS all” This revealed a desire to normalize eccentric behaviors and connect with a group of people similar to themselves. Participants described a sense of relief after receiving their diagnoses. Once they began to learn about the syndrome, many of the unusual behaviors they demonstrated were normalized. This brought about an ability to cast off feelings of shame and self blame. During the interviews, every research participant made generalizing

statements about “people like us,” which demonstrated the desire to be connected to others.

Bodyhood.

For the adult with AS, the universal structure of bodyhood is distinguished by both a heightened sense of physical excitement, feeling “floaty” and an inability to locate their bodies in space. Research participants also spoke of feeling “scattered brained” and how their special interests provided a place for them to “put” their “minds on.”

Temporality.

Time was experienced on numerous levels. The research participants described the time they spent engaging in their special interests as passing rapidly. One individual acknowledged he could “escape” into his special interest for hours. Some indicated they could talk about their special interests for “hours;” similarly, time was “filled up” and “flew by.” One research participant stated he would “set time aside” to engage in his interests.

Participants tended to quantify aspects of their time. This was evidenced by their earmarking events with dates and times. They also specified how old they were when their activities began, and noted how many years they had been engaged in a particular pattern. The need to quantify aspects of their experience points to a desire to create order out of perceived chaos.

Spatiality.

For these research participants, space was described as unending. The special interest was something one could become “lost in” or “delve into,” or “put their minds on” to avoid feeling “scattered.” Special interests provided a sense of grounding and

connectedness that anchored the participants, and were also utilized to connect to the physical world and counterbalance feelings of weightlessness or “floating.”

Also, special interests were described as expansive, in that new worlds could be opened and revealed. Some participants utilized the concept of “tunnel vision” to describe a laser-like focus they possessed while engaging in their special interests. This revealed a narrowing and lengthening of space.

Causality.

The structural element of causality possessed two elements: 1) the double bind; and 2) choosing predictable objects instead of unpredictable people.

The double bind refers to the inherent paradox associated with special interests. The interests, which were selected as a way to opt out of the social milieu, also provided an opportunity for social connection. However, these interests became so absorbing that individuals with AS found themselves even *more* socially isolated.

Choosing predictable objects instead of unpredictable people can be viewed as a direct cause and effect response. The social world and people in it are inherently unpredictable, causing the adult with AS to experience anxiety. Therefore, the person with AS chose to spend his or her time focused on predictable objects or unchanging aspects of their special interest in order to ease their angst.

Synthesis

The synthesis represents a composite of both the textural and structural themes extracted from the data. It is a culmination of the noema and noesis, a comingling of the aspects of the *what* and *how* that comprises the totality of experience. In the synthesis, the primary researcher's goal is to identify the pure essences inherent in the particular

phenomenon being explored. In this investigation, the primary researcher sought to gain a deeper understanding of special interests and what they mean to adults with AS. The data revealed in this chapter represents the textural and structural elements that provide a window into the world of special interests.

For those who feel different in a world that is unpredictable and overwhelming to the senses, a place where people can be cruel and unkind, the special interest offers a retreat. It provides a destination where one can escape and therefore manage the feelings of constant anxiety. Once the individual arrives at and begins to engage in his or her special interest, he or she is welcomed into a world of calm and peaceful bliss. There is no one there who will bully, abuse, or bother them. They can control and manipulate all aspects of their environment.

The special interest allows the adult with AS to focus and improve his or her attention. Instead of feeling altogether detached, flipping from one thing to the next, or floating in space, the individual with AS feels anchored and connected to the world. Time passes rapidly in acts of repetition, where comforting sounds and images wash over like a purifying elixir.

But there is danger in allowing oneself to become *lost* in special interests. Aspects of addiction and compulsiveness can come into play and can increase or exacerbate social isolation. The rest of the world begins to slip away, as if the adult with AS has travelled inward and down a long and narrow tunnel. He or she begins to lose sight of the universe and is only aware of the special interest, the saving grace.

The adult with AS wishes to connect with others. There is a need to be valued and respected and the special interest offers a way to stand out from the crowd and be

recognized and appreciated. Becoming the local expert or a person who can answer questions about inane facts, even making “United States famous” cookies, are all ways to be recognized and valued in the world.

Another way to connect with others is by identifying with individuals who have been diagnosed with AS. This provides a sense of belonging and a way to normalize eccentric behaviors.

Adults with AS recognize they are different from the *neurotypicals* who populate this planet. They describe themselves as “Aspergery” or “Aspy” like. While on the one hand, they realize their differences and how that separates them from others, there is a sense of superiority that accompanies the diagnosis of AS. The research participants acknowledged that people were “amazed,” “impressed” and “influenced” by their abilities. They affirmed that while AS has made their lives difficult in many ways, it has also made them more interesting people. One participant “thanks God” for his special interest.

The synthesis concludes with a poetic effort to summarize the essences of the research question, *How does an adult with AS experience his or her special interest?*

Order, count, gather, sort
 Get the book, get the fact
 I must have that last one
 Complete my collection
 Order, count, gather, sort
 Laser powered focus
 Shut out the whole world
 I will allow you to be my witness
 I will narrate my experience
 I could go on and on and on
 Order, count, gather, sort
 Forced relationships
 Forced connections
 Forced normalcy

Order, count, gather, sort
The social world is a code
I can't seem to crack it
It is hidden from my view
Order, count, gather, sort
I can demonstrate my knowledge
I can demonstrate my value
I count

In this chapter, the findings of this research study were presented. A summary of prior chapters is presented in the next chapter, and the research findings are compared to the review of literature presented in Chapter II. Also presented in Chapter VI are the limitations of this research and recommendations for future studies. Finally, the implications and applications of the research are analyzed, and the social relevance of the study is presented.

Chapter VI

Discussion and Conclusions

This chapter provides a summary of the study. Current findings are compared to the information revealed in the literature review, the investigator proposes future research that might prove beneficial based on the current findings, and the social relevance and limitations of the research are described. Lastly, the researcher describes the experience of completing the study and how it may impact the future of those diagnosed with AS and the people who work to support and assist in their development.

Review of Chapters I Through V

In Chapter I, the meaning of the research question was revealed. The chapter explored the personal and professional relevance of the study, stated the research question, and defined the terms.

Chapter II examined the scope of relevant literature on adults with Asperger's syndrome and their special interests. The review provided a comprehensive historical accounting of the available literature, revealed the academic debate regarding diagnostic criteria for AS, demonstrated the researcher's knowledge in the area of autism, and positioned the study as a unique contribution to the existing body of research on special interests and Asperger's syndrome.

Chapter II was organized into six primary categories: 1) the criteria for diagnosing Asperger's syndrome and how that relates to special interests; 2) an overview of research regarding the functional, developmental and evolutionary aspects of special interests; 3) the neurology of special interests and savant syndrome; 4) the pathology of special

interests; 5) giftedness and special interests; and 6) a review of qualitative and quantitative studies that pertain to Asperger's syndrome.

In Chapter III, the rationale for the selection of the qualitative research model was discussed, the history and genesis of the Transcendental Phenomenological model was explained, and a description of the model's steps, theories, and concepts were identified and defined.

Chapter IV revealed the methods and procedures used for maintaining confidentiality in addition to the preparation for data gathering, organizing and synthesizing the data. Also, a brief demographic overview of the research participants was provided.

In Chapter V, the data illustrating the essences of how adults with Asperger's syndrome experience their special interests was presented. The textural themes were first identified and described, the researcher provided three individual textural descriptions that encompassed the primary textural themes, and a composite description that illuminated the noematic aspects of the experience. Next, the data was presented according to the seven universal structures, also referred to as the noesis. The structures included relationship to self, relationship to other, materiality, temporality, causality, spatiality and bodyhood. Three structural descriptions were specified, followed by the composite structural description, which highlighted the main structural themes. The final step brought together the noema, the *what*, and the noesis, the *how*. Lastly, the synthesis integrated the thematic essences found in the data.

The Findings

The three textural themes identified were: 1) coping, 2) addiction, and 3) valued and respected. First, the special interests were utilized as a way to cope with life. The research participants described a world that felt overwhelming. Their ability to understand the social demands, academic challenges and sensory stimulation created a tremendous amount of pressure for those adults interviewed for this study. By engaging in clear, concrete, unambiguous activities, the circumscribed interests provided a way to ease the mounting pressures they felt from their environment. The time spent engaged in their passions alleviated the stress and helped them manage a sense of equilibrium. The four components of the textural theme of coping included four sub components: 1) The research participant used their special interests as a way to anesthetize or numb themselves to the outside pressure and thereby escape; 2) Knowing they had the ability to escape created a sense of calm and a feeling of peace; 3) The interests provided a way for them to focus their attention on one particular subject and ignore extraneous stimuli; and 4) The research participants indicated feeling out of control and described a need to make order from the perceived chaos. Selecting highly predictable special interests with a focus on static objects such as trains, railway signs, and game shows provided a measure of predictability. The special interests were unchanging and that provided a sense of control that brought with it a sense of relief and an ability to cope with the unpredictability they experienced throughout the day.

The second textural theme was addiction. Many of the research participants spoke of a heightened sense of excitement while engaging in their area of interest. Aspects of bliss and physical reactions, which included sexualized responses and euphoria, were

evident in research participant data. When viewed through the lens of addiction, the special interest became like a drug. The research participants reported feeling intoxicated and stimulated while engaged in their special interests, co-mingled with an almost religious-like fervor. Yet along with the *high* the research participants experienced, they also noted feeling addicted to, ruled by, and obsessed by their special interests.

The third textural theme was being valued and respected. The development of a special interest may be viewed as a direct response to the human need to be appreciated, esteemed, and noticed. Attwood (2003) indicated that individuals with AS were often characterized as “little professors” and they were known to gather and memorize encyclopedic amounts of information on their selected subject matter. For the adult with AS, being valued included being known as the local expert or the person who could provide answers. Gaining expert status, according to the research participants, was the primary avenue used to earn the appreciation of others. It also held a certain amount of status and could provide opportunities to be recognized, appreciated, and admired. In the following section the structural themes are reviewed. Next, the structural themes representing each universal structure are revealed.

Relationship to Self

The primary researcher identified two elements that appeared for the majority of research participants: focus and calming. The participants reported difficulty harnessing their attention and controlling their anxiety when interacting in the neurotypical world. Special interests helped them cope by heightening their attention and settling their nerves.

Relationship to Others

Relationship to others yielded the following three elements: 1) Special interests established a bridge to social connection by being the expert; 2) "Data dump," the tendency to repel others by revealing too much about their special interest, and; 3) Research participants created a group identity, by utilizing terms such as: "People with AS tend to be . . ." or "All people with Asperger's syndrome are . . ." They used these phrases to normalize their eccentricities and identify with others like themselves.

Bodyhood

The universal structure of bodyhood is characterized by both a heightened sense of physical excitement, which manifests as jumping, handflapping, pacing, and an inability to locate their body in space or feeling "floaty." Research participants experienced special interests as a place to emotionally and mentally retreat, inferring that without the special interest they would be lost or "scatter brained."

Temporality

According to adults with AS, time passed rapidly while they engage in their special interests.. One individual stated the world would "open up" and he would escape for hours. Some participants affirmed they could talk about their special interests for "hours." Similarly, time was "filled up" and "flew by." One research participant indicated he "set time aside" to engage in his special interests.

Spatiality

Space was described as bottomless. The special interests became something to get "lost in" or "delve" into. Individuals could "put their mind on" their special interests to avoid feeling "scattered." The participants reported feeling a sense of grounding,

connecting, and anchoring while engaging in their interests. Special interests were also used to connect to the physical world to combat the feelings of weightlessness or “floating.” Special interests were described as expansive in that new worlds could be “opened” and revealed. Some participants utilized the term “tunnel vision” to describe a laser-like focus they possessed while engaging in their special interests. This suggested a narrowing and lengthening of space.

Causality

The structural element of causality possessed two elements. 1) The double bind and; 2) choosing predictable objects instead of unpredictable people. The double bind referred to an inherent paradox in the special interest. On one hand research participants utilized their knowledge of their topics of choice to impress and engage other people. However, “addictive” or “obsessive” aspects of special interests could cause the participants to withdraw socially and increase their sense of isolation.

Choosing predictable objects addresses the tendency of the adult with AS to gravitate towards activities that are typically one dimensional and offer no surprises; the causal relationship being that the world is highly unpredictable, therefore, time and attention is spent on aspects of the environment that can be controlled.

Prior Research and the Current Study

Bashe & Kirby (2001) surveyed more than 100 parents of individuals diagnosed with AS. Each confirmed that their child had one or more special interests. The research participants in the current investigation provided similar information regarding their special interests. Nine of 12 confirmed they have had multiple special interests over the

course of their lifetimes. In addition, the participants revealed they have multiple, co-occurring special interests.

However, three of the four females interviewed did not possess special interests; their fascinations would be categorized as hobbies. Faherty (2006) confirmed this finding and reported that the disorder of AS manifests in different ways for females. Further, Gillberg and Coleman's (2000) research results indicated females with AS have fewer special interests than males. It is important to note that in this investigation the majority of female participants did not possess special interests, also indicating possible gender distinctions in Asperger's syndrome and special interests.

In conjunction with the appearance of multiple interests, the research revealed that special interests remained a primary characteristic of the individual with AS (Bashe & Kirby, 2001; Kerbeshian, Burd & Fisher, 1990; Tantam, 1991). Also, studies confirmed that special interests remained stable over time (Piven, Harper, Palmer & Arndt, 1996). The research participants in this study confirmed these results. The majority of participants indicated a lifelong history and relationship with their special interests. These early memories affirm the finding that special interests are a stable and primary characteristic of AS. It is important to point out that in this investigation the majority of female participants did not possess special interests. This suggests the meaning and symptoms of Asperger's syndrome may have significant differences for females and males.

Attwood (2003) reported that individuals with AS possess a preoccupation with parts of objects. An example of this would be an interest in the wheel on a toy car versus the car itself. Baron-Cohen and Wheelwright (1999) discussed that special interests

tended to be object focused rather than people focused. The concepts of a preoccupation with a part and being object focused also were evident in the results of the present study. Research participants provided numerous examples of their unique fascinations with esoteric aspects of cartoons, game shows, music, and components of bicycles. Rather than being interested in a cartoon's story line or the content of a game show, however, the participants were fascinated by production dates, scratches on the film, voices of the game show announcers, or the pieces of bicycles. Research participants' interests were peaked by aspects that were unrelated to human connection or emotional understanding.

Attwood (2003) hypothesized that special interests serve various purposes for those with AS, such as decreasing anxiety, increasing relaxation and pleasure, ensuring predictability, creating meaning in the physical world, escaping from the current reality, building identity, elevating social status by becoming an expert, and occupying time. Each one of these themes is supported in the present study. Special interests were described as a way to cope with the outside world and decrease anxiety in the face of social interaction and the demands of parents, teachers, and therapists. The research participants indicated that they used their special interests to feel a sense of competence and worth. Lastly, participants indicated that engaging in their special interests was a way to focus their attention and fill their time.

Turner (1999) researched the unusual behavior often exhibited in autism and AS. He categorized these mannerisms into low and high-level repetitive behaviors. Turner indicated individuals with classic autism demonstrated low-level behaviors such as jumping, arm flapping, or rocking; whereas high-functioning people diagnosed with autism demonstrated high-level behaviors such as circumscribed interests. The results of

Turner's study did not address how some individuals with AS exhibit both high and low-level repetitive behaviors.

The findings of the present study indicate that high-functioning individuals exhibit both low and high-level behaviors. The high-level behaviors are evidenced in the research participant's bodily reactions while engaging in their special interests. One participant indicated that he paced, jumped, and flapped his arms while watching his game shows or tennis matches. Another participant indicated that while watching his cartoons he often waved his hands or blew on his arms.

Dabrowski (as cited in Webb, Amend, Webb, Goerss, Beljan, & Olenchak, 2005), discussed how over-excitabilities that characterized the heightened sensitivities and mental abilities of a gifted person might also apply to the population of individuals with AS. Dabrowski indicated that there are five areas of overexcitability: intellectual, imaginal, emotional, psychomotor, and sensual. The participants in the current study indicated that while engaging in their special interests they felt an automatic reflex to move their bodies. This finding might indicate some overlap in the literature of Asperger's syndrome and giftedness.

In conjunction with the literature on giftedness, Treffert (2000) wrote about the exceptional skills of people with savant syndrome. According to Treffert, three primary categories of savant syndrome exist. The most common category described those individuals who possess splinter skills, which Treffert described as a person who is an obsessive hobbyist that memorizes and amasses huge amounts of statistical information. In this study, 7 of the 12 research participants demonstrated splinter skills. Unique to this study is the indication of overlapping criteria between savant syndrome and AS. Aside

from Treffert, little has been written about the shared attributes of the two disorders. Later in this chapter, the implications of using a savant syndrome treatment approach with the AS population will be discussed.

Baron-Cohen and Wheelwright (1999) attempted to parse out differences between Obsessive Compulsive Disorder (OCD) and special interests. They determined that the special interests of a person with AS are unlike those with OCD, where the obsessive thoughts are unwanted. Conversely, in the current study the research participants spoke lovingly and fondly of their special interests, in spite of the fact that they also referred to them as obsessions and/or addictions. In this study, the special interests provided a way to cope, and a metaphoric place to escape to in a chaotic world. Some overlap may exist between OCD and AS, but there are clear differences in the two diagnostic categories that should be further understood and explored in future studies.

Further Research Opportunities

Based on the findings that special interests can become addictive, the primary researcher proposes a quantitative study that investigates the neurological differences between addictions to drugs and alcohol, obsessive compulsive disorder, and Asperger's syndrome and special interests. Functional magnetic resonance imaging (fMRI) scans could be used to determine which parts of the brain are being activated in each of the three groups while they are actively engaged in thinking about their obsessive or addictive behaviors.

The research participants would be made up of three separate groupings: 1) adults with AS; 2) adults diagnosed with obsessive compulsive disorder; and 3) adults diagnosed with addictions to either drugs or alcohol. Each group would consist of one

hundred or more individuals who previously received from a licensed mental health professional a diagnosis of AS, obsessive compulsive disorder, or addiction to narcotics or alcohol. The participants would be shown pictures of items that stimulated thoughts of their special interests, obsessive rituals such as hand washing, or scenes of substance use. The fMRI scan would monitor brain activity while these individuals were exposed to specific images that trigger obsessive or addictive thoughts. Results would reveal the differences or similarities inherent in these three separate neurological disorders.

A second research proposal would utilize the case study model, a qualitative method that includes a detailed description of a particular individual based on careful observation. According to Wade & Travis (2000), case study offers “. . . information about the person's childhood, dreams, fantasies, or anything that will provide insight into the person's behavior” (p. 38). The primary investigator would present an in-depth look at the experience of special interests. For the purposes of this study, the investigator interviewed the required minimum of 12 participants, which prohibits a more exhaustive view of the special interest. The case study model allows the researcher to focus his or her time and attention on fewer participants, yielding a more comprehensive understanding of the effect and impact the special interests have on the adult with AS. This model would also allow for more flexibility on the part of the researcher. He or she could observe the participant in a variety of settings and interview relatives, teachers, friends, and employers that could provide insight on the impact of special interests and how they help or hinder the individual with AS.

Lastly, the primary investigator proposes conducting a large scale survey about the special interests of adults with AS. In the present investigation, the primary researcher

selected a model that utilized a limited pool of participants. The use of a survey instrument would provide the opportunity to collect data from an unlimited number of subjects. Over the last five years, a number of websites have been created for individuals diagnosed with Asperger's syndrome; one such website is Wrong Planet.com. On this website people can inquire about and discuss many aspects of the AS experience.

The use of an online survey, which could be administered over this type of website, has the potential of reaching thousands of people. With appropriate processes in place, the large pool of potential participants could yield a wealth of statistically relevant data. Questions about special interests would be set up using a Likert Scale, and participants would be instructed to check boxes that most accurately reflect their experiences. For example: "I engage in my special interests 8-10 hours per day." The participant would select one of the following: *strongly agree*, *agree*, *uncertain*, *disagree*, *strongly disagree*. Categories of questions would cover some of the following topics: types of special interests, i.e., music, mechanics, sports, trivia; amount of time spent engaging in special interests; impact of technology; extent to which special interests have provided a bridge to social interaction or created a deeper sense of social isolation; and to what degree special interests have helped or hindered employment opportunities. The information gathered from adults with AS would provide insight into the meaning of the often misunderstood special interest, and benefit individuals, children, families, and mental health professionals touched by Asperger's syndrome.

Social Relevance

According to the Autism Society of America, (2008), autism is on the rise and services are in great demand not only for the individuals diagnosed, but also for their

parents, siblings, extended family members and professionals. Receiving services is a constant struggle for these families, and autism specialists are relatively rare (Sicile & Kira, 2006). If more mental health professionals, teachers, doctors, speech pathologists, and neurologists became aware of the special needs that are present for families when they receive the autism diagnosis, then those involved would be more sensitive and responsive to the needs of the children and families effected by AS. These professionals are all part of a multidisciplinary team whose intention is to diagnose and treat an individual with autism and his or her family. Based on the clinical experience of the primary researcher, very few of these professionals are prepared to address the unique demands required to work with families that have a child diagnosed with autism.

According to Bolman (2006) 80% of parents with an autistic child will be divorced. Siblings of an autistic child are likely to suffer anxiety and depression due to the financial and emotional stresses that autism places on their parents (Aston, 2005). It is likely that those in the mental health field, without specific training in autism and the effects it has upon a family, would fail to treat the situation with an appropriate, empathic awareness or have the overall knowledge needed to create a wide-ranging and effectual treatment strategy.

Comprehensive seminars and courses should be made available to those professionals who are currently working with or are interested in working with individuals touched by autism or AS. Specific classes can provide an opportunity for those in the field to increase their consciousness regarding the issues related to autism. At best, they would then be in a position to incorporate new understandings of autism into their practices with current or newly referred clients.

The goal of this research was to help professionals, parents, and educators understand the function and nature of the special interest in AS as an adaptive skill versus a liability. To truly understand the experience of having a circumscribed interest, one must look through the eyes of the person diagnosed with Asperger's syndrome. The interest can be seen as either a barrier or a social, educational, or therapeutic opportunity.

Much of the current literature reviewed by the primary investigator focused on the management of special interests. Behavioral therapists create treatment plans with the goal of extinguishing special interests that are regarded as addictions. While there may be aspects of the unique interests that need to be managed, it seems important for those who work and live with individuals with AS to understand more about the nature and function of the special gifts and limitations that dwell within them.

Study Limitations

The four key study limitations identified by the primary investigator:

- 1) Small sample size
- 2) Lack of responsiveness/communicative challenges with female participants
- 3) Fear of tainting the research by asking direct questions
- 4) Lack of local participants required phone interviews

Small Sample Size

Due to the small sample requirements of the Transcendental Phenomenological model (12-15 research participants), the results of the study are not statistically significant. Therefore, the findings, while descriptive of the experience of special interests for those with AS, are not generalizable to the overall AS population.

Lack of Responsiveness and Communicative Challenges with Female Participants

Three of the four females interviewed for this study had difficulties communicating and responding to the questions asked during their interviews. When they did answer, the responses were often brief. When the primary investigator probed further about a particular subject, oftentimes the female participant indicated that she did not understand the question. The communicative challenges were not evident during the brief screening performed by the primary researcher; however, during the course of the interview, there was an obvious inability for certain female participants to relay or articulate their experiences regarding special interests. Also, three of the four female participants did not describe their special interests with the same intensity as their male counterparts; the majority of female participants characterized their interests as hobbies. The challenges with communication and the characterization of special interests as hobbies pose both a limitation and a significant finding. The females presented with obvious language deficiencies that limited the primary researcher's ability to clearly understand their experiences. The fact that the females' special interests did not manifest the same way as the males also indicates both a lack of data and a relevant finding that should be explored in further research.

Fear of Tainting the Research by Asking Direct Questions

In a qualitative study, participants' responses serve as the data that is later transcribed and analyzed. The researcher is instructed to be wary of tainting their research participants' responses, which can be easily done by an overzealous or inexperienced interviewer. The primary investigator did her best to remain impartial, aware that the slightest utterance could render the results of the interview unusable.

According to Attwood (1998), the AS population often has difficulty with language; they can either speak volumes about their special topics or be unresponsive. The open-ended interview format worked well for those participants who liked to speak about their special topics. With others, the interviewer had to work very hard to encourage them to stay on topic or feel comfortable enough to speak at all. The investigator was forced to change her interview strategy based on the specific needs of the research participant. The inconsistent interview style utilized by the primary researcher could therefore be considered as a limitation of this study.

Lack of Local Participants Required Phone Interviews

The primary researcher conducted four of the twelve interviews via telephone and as such, was unable to view and assess the nonverbal gestures, appearance, and facial expressions. The investigator also felt it was difficult to establish a solid rapport with telephone participants prior to the beginning of their interviews. Finally, due to poor overseas connections and lack of clear pronunciations, some of the interviewee's responses were inaudible and were not transcribed.

However, for the research participants the phone interviews had clear advantages. Attwood (1998) indicates that individuals with AS have difficulty with eye contact and often feel uncomfortable when they have to veer from routines. The phone interview allowed research participants to remain in the comfort of their homes and familiar surroundings. Their routines did not need to be altered and they were not forced to make eye contact. In this way, the phone interviews may have actually proved advantageous for the research participants.

Experience of Completing the Study

The primary researcher's initial passion for the topic of individuals with AS and their special interests was ignited through witnessing the excellence they achieved in becoming experts on their selected subjects. The researcher's own admitted learning difficulties created a wondering as to how people diagnosed with learning challenges overcome their unique set of obstacles and manage to achieve a level of brilliance. For the researcher, there is nothing more gratifying and exciting than listening to people who speak passionately about something they enjoy. The excitement the research participants possessed and articulated was contagious, and inspired the investigator to complete the study in spite of many obstacles encountered during the process.

The goal of this study was to better understand special interests from the perspective of the individual diagnosed with AS, and for professionals and parents who engage with this population to understand the role of the special interest and possibly use it as a tool and/or point of emotional and intellectual connection. The research findings indicate that special interests are used by those with AS to manage anxiety and escape a confusing and sometimes cruel world. Special interests also represent a way to elevate social status and connect with others. These findings present a therapeutic pathway for teachers, mental health professionals, speech and occupational therapists, medical doctors, and parents to bond and open up a more communicative world for the individual with AS.

The research findings also indicate a need for more research to delineate the differences between obsessions, addictions, and special interests. There are aspects of

special interests that need to be managed or closely watched to reduce the likelihood that the lives of individuals with AS become dominated by their interests.

The special interests of adults with Asperger's syndrome represent "islands of genius" according to Treffert (2000). In this book, Treffert posed the question: What treatment approach should be considered for the savant? Is it better to train the talents or eliminate the defects? According to Grandin and Duffy (2004), if the talents are trained, the defects will naturally decrease or subside. Therefore, these "islands of ability" that Treffert (2000) discussed, "the islands of genius" provide an opening of opportunity for the professional treating someone with AS. Using Treffert's (2000) concepts and applying them to the AS population, one could assume that the special interests are a way to facilitate rapport, create an opportunity to make contact, and form a relationship with the individual with Asperger's syndrome.

A number of schools have emerged that utilize the concept of "train the talent," such as the Soundscape Center in London, which specializes in developing the potential of the blind and those with musical talents. Orion Academy in California creates a positive educational experience for high school students with AS. Similarly, Hope University in Anaheim, California serves to educate and develop the strengths of those with developmental abilities through the use of drama, art, storytelling, music, and dance. Clark (2001) employed a Savant Skill Curriculum for children with autism. His case study research utilized strategies saved typically for the education of gifted children, which included enrichment, acceleration, and mentorship in conjunction with visual supports. This unique curriculum attempted to address the splinter skills of savants and children with autism. According to Clark (2001), his study proved to be highly successful

and he reported an overall reduction in the level of autistic-like characteristics in his study subjects. Clark documented reduction of disruptive behavior, improvement in social skills and academic achievement, and increased self-esteem.

Based on the findings of this study, the primary researcher plans to continue her work with individuals diagnosed with autism and Asperger's syndrome, and to incorporate her newfound knowledge into her clinical practice. The data gleaned from this study suggests special interests play an important role in the lives of adults with AS. It provides them with the means to cope, elevate their social status, and connect with other people. Clinicians can benefit from this knowledge as well, and the researcher plans to integrate these findings into her training with other mental health professionals, teachers, and parents on how to utilize special interests to motivate those diagnosed with Asperger's syndrome to move toward the realization of their potential.

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APPENDIX A

Adults with Asperger's Syndrome Needed for Qualitative Research Study

Seeking adults 18 and above who have been diagnosed with Asperger's Syndrome for a research study exploring the experience of special interests.

The special interests are typically topics or items of interest such as the civil war, music, vacuum cleaners, or cars. The adult with AS can have evolving special interests that have changed but what remains consistent is the time and energy spent on collecting encyclopedic amounts of information on his or her special topic. Often these interests are described by others as obsessions.

The research participant would be required to participate in a 90 minute interview and if necessary a follow-up telephone conversation.

Please contact me if you or someone you know fits the criterion and would like to participate.

Katie Kramer, MA, TLLP, Psy.S.
Doctoral Candidate
Michigan School of Professional Psychology
xxx-xxx-xxxx
Katie.xxx@xxxxxxx.xxx

APPENDIX B

Invitation Letter to Research Participant

Dear _____:

Thank you for your interest in my dissertation research on "*how adults with Asperger's Syndrome experience having a special interest.*" Based on our previous contact our interview is scheduled for _____ at the following location _____. Should you have any questions or concerns prior to the interview, I can be reached by cell phone at _____ or by email at _____.

The research model I am using is qualitative. This type of research seeks to uncover comprehensive depictions and descriptions of your experience of having special interests. The interview will last approximately 90 minutes and will be audio taped in order to transcribe the details of our interview. Enclosed you will also find a letter containing ways for you to prepare for our meeting as well as a release form that needs to be signed prior to commencing the interview.

Please feel free to bring anything to our meeting that will help you in your process of describing your special interest. Items such as books, graphs, recordings or drawings can be discussed and described during our time together.

Best regards,

Katie Kramer, MA, TLLP, Psy.S.

APPENDIX C

Informed Consent for Research Participants

Principle Investigator: Katie Kramer, MA, TLLP, Psy.S.

Faculty Supervisor: Lou Katz, Ph.D. at 248-476-1122

PLEASE READ THIS DOCUMENT CAREFULLY. SIGN YOUR NAME BELOW ONLY IF YOU AGREE TO PARTICIPATE AND FULLY UNDERSTAND YOUR RIGHTS. YOUR SIGNATURE IS REQUIRED FOR PARTICIPATION. YOU WILL BE GIVEN A COPY OF THIS DOCUMENT.

All research participation is voluntary, and you have the right to withdraw at any time, without prejudice, should you object to the nature of the research. Your responses are confidential. Any report of the data collected will not contain identifying information about the research participant. You are entitled to ask questions and to receive an explanation. If you have concerns about your participation in this study, you may contact:

Principle Investigator: Katie Kramer, MA, TLLP, Psy.S. at (xxx) xxx-xxxx

Doctoral Chairperson: Lou Katz, Ph.D. at 248-476-1122

Description of the Study

This research question is "How does the adult with Asperger's Syndrome experience having a special interest?"

Nature of Participation:

Each interview will last approximately 90 minutes and will be audiotape recorded. The interview will take place at my office or in a location to be determined. If necessary, alternate arrangements will be made to accommodate your schedule.

Purpose of the Study:

This study will focus on understanding the experience of a person with Asperger's syndrome and their special interest.

Possible Risks:

You will be asked to participate in an interview that requires you to share personal information about yourself. There are no anticipated risks in this study, though it is possible that some discussion may evoke uncomfortable feelings. If there are concerns or discomfort, you may choose not to respond or withdraw entirely from the research at any time. A referral for a mental health professional will be provided by the researcher, should it be deemed necessary, or if requested by the research participant.

Possible Benefits:

You will have the opportunity to contribute to psychological science by participating in this research. You may find it interesting and enriching to share these experiences. This will be an opportunity to raise awareness of the phenomenon of Asperger's syndrome and special interests. Such awareness may benefit the field of psychology and other mental health professionals and society at large to improve the quality of services rendered.

Confidentiality:

The original recording and transcript of all interviews will be kept in a secure location to protect your privacy and retained for a maximum of 5 years prior to destruction of tape recordings. Your name will not appear on the audio recording or transcription. Participants in this research will only be identified in general demographic terms (e.g., participant B is a 36-year-old female who practices psychotherapy in an urban setting) in the dissertation manuscript and any subsequent publications. The chair of my committee and a transcriptionist may hear your audio recording and could conceivably identify your voice although it would be unlikely that either would be familiar with you.

State law requires appropriate notification of designated others in the event that you reveal that someone, including yourself, is in danger of serious harm. Such harm includes, but is not limited to, abuse, neglect or threats of harm to self or others.

Opportunities to Withdraw at Will:

If you decide at any point to withdraw this consent or stop participating, you are free to do so without penalty or prejudice. You are also free to skip specific questions or discontinue participating.

Opportunities to be Informed of Results:

If you wish to have a summary of the results, complete the following:

Name: _____

Address: _____

E-mail (optional): _____

Thank you for taking the time to share your experiences.

I voluntarily sign this document and further acknowledge that I have understood and received a copy of this consent form.

Signature of Participant

Date

Signature of Primary Researcher

Date

APPENDIX D

Definition of Key Terms

Adults: Kazdin (2000) states that the primary theorists on adulthood and aging describe adulthood as a time where a person begins to “. . . make commitments to social roles builds on resources of personality developed earlier in life. In turn personality develops in roles and contributes to further personality growth, which leads to happiness and well-being in later life” (p. 81). For the purpose of this study, adulthood will include people from the ages of 25 and up to but no older than 50 years of age.

Asperger Syndrome: The Diagnostic Statistical Manual of Mental Disorders 4th ed.-Text Revision (DSM-IV-TR) (2003) defines Asperger's Syndrome:

. . . a qualitative impairment in social interaction, manifested by at least two of the following: (1) marked impairment in the use of 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 of other people (4) lack of social or emotional reciprocity (Kluth, p. 7).

For the purpose of this study the research participant must have a diagnosis of Asperger's syndrome given to them by a school, mental health professional or medical doctor.

Experience: Includes everything accessible to the conscious mind such as any sensory (sight, sound and smell and taste) perception. The individual can consider the special interest and describe any sensory or bodily awareness they have while engaging, thinking about or describing their relationship to their special interest.

Special Interests: The person with AS spends enormous amounts of time gathering information, researching, and discussing his unique and sometimes esoteric special interest. Attwood (1998) states that people diagnosed with Asperger's Syndrome have “. . . a special interest such as transport, animals or science. These interests come and go but dominate the child's free time and conversation” (p. 14). He goes on to discuss the fact that often a person diagnosed with AS has “. . . remarkable long-term memory, exceptional concentration when engaged in their special interest and [have] an original method of problem solving” (p. 9). According to Attwood (1998), any topics or tasks that fall outside the area of interest are met with “. . . a lack of motivation and attention” Special interests have also been referred to as obsessions and for the purpose of this study either will be considered appropriate to discuss.

APPENDIX F

Coded Horizons

Table2. Coded horizons.

APPENDIX G

Sample Verbatim Interview

Katie: Okay, we are recording and today is October 28, 2007, I'm Katie Kramer and this is A4. We are going to be discussing the question how does the adult with Asperger's Syndrome experience having a special interest? And so the first question I'm going to ask A4 is, what do you remember about your first special interest?

A4: What do I remember about it? Well it's probably my love for cooking, which is what I have done all my life; and I would assume that it came at a very young age since I've enjoyed doing it all my life and that's probably the first interest that I really ever had and still do have.

Katie: Do you remember how old you were?

A4: I was young and I don't know at what age, but I remember doing it as long as I can remember all my life so it could be anywhere as young as eight or nine. That's just a guess because I've enjoyed doing it and that's what I've made my career out of.

Katie: That's a pretty young age to start cooking, so who were you with?

A4: Who maybe influenced me? Well my mother, my grandmothers. We had a lot of good cooks in the family and they always cooked so I loved to cook and one thing led to another and it's what I've done for 21 years.

Katie: How did it, in terms of the beginning of it, would you cook with them or were you cooking by yourself at the time?

A4: Well I just always enjoyed being in the kitchen and wanting to help and wanting to be a part of it and learning things from them that I've enhanced upon and made better. Things that they would make that they would have been known for but now I'm known for, maybe even better.

Katie: Wow, can you give me an example?

A4: Different things. My grandmother used to be known for her chocolate chip cookies, and now my cookies have become United States famous, and just different things that they've done that I have now taken over and made better and improved upon.

Katie: And tell me what areas in terms of the cooking, besides the actual cooking of itself, was of interest to you?

A4: Beside cooking, I've always enjoyed it, and I've enjoyed watching it. I've enjoyed it on television and with the *Food Network*, I've enjoyed hands-on work. I've always been a showman; and sometimes I can envision myself in their place when I'm cooking something, as if there's an audience when there really isn't.

Katie: Tell me more about that?

A4: Well, I'm not saying a double personality, but I'm saying from the standpoint that, like you're envisioning; that you're in a studio of some kind, and you have an audience, and you're cooking in front of an audience.

Katie: Okay, almost like an instructor?

A4: Almost like you're doing this and you're doing that.

Katie: As you are cooking in the kitchen, it will be playing in your head.

A4: It could be.

Katie: Any famous chefs that influence you, besides your grandmothers?

A4: I've met a bunch of the well-known chefs across time. People like Emeril and Mario and some of the bigger names I've spoken with, and yeah, I've run across a few.

Katie: Cooking has been your first special interest and it stayed with you the whole time.

A4: It stayed with me for a good while, yep.

Katie: Can you tell me something about some of the other special interests that you have?

A4: Some of the other special interests that I have well, there's a couple more I'm sure. My country music.

Katie: Say more about that.

A4: Country music is one of my passions; not because I play an instrument. though I'd like to learn someday, but because I enjoy the music. It's all about real life and real music. I just returned from my 21st year down in Nashville; 25th visit, 21st year with my father. It's been our annual trip since 1986. I enjoy meeting the artists and meeting the fans, and I've made a lot of friends through that. That goes probably back at least 25 years. I basically remember a paper we had to do in school that has some musical influences, and I remember putting touching music and artists down of the day, so I know it's at least 25 years that I've been affiliated with that. Bowling is another one that I really enjoy. I bowl in a league Sunday mornings, and I used to bowl in a youth league when I was younger and won a lot of awards for my bowling, not any more. So I got a lot of things; game

shows and old television and soap operas, different things that I enjoy; nothing really current; all in the past, basically.

Katie: So game shows, soap operas.

A4: So game shows, old television, soap operas.

Katie: What does old television mean?

A4: Meaning that programs that were around say 20 years or beyond; nothing of the current genre on national television, but things that you find on TV Land for instance.

Katie: Right, TV Land?

A4: Right. Situation comedies and family programming and all kinds of things that happened in the past quality program that you don't find today.

Katie: Give me an example.

A4: An example, *The Courtship of Eddie's Father*, *The Waltons*, *Eight is Enough*, *Alice*; all kinds of different programs that were great quality programming that we don't find today on television.

Katie: Are there anymore you want to list at this time?

A4: That gives a pretty good idea, I think.

Katie: Would you say community service has become one of your passions?

A4: I think so. I do a lot of it. This week for the first time I'm going with a couple of people to Children's Hospital, and one of my friends is involved there and she's taking me and this other guy with her to see what that's all about. So maybe we can start an involvement done there, so I'm gonna check that out. It's not people

with Aids; not children with Aids, but it's children affected by Aids in some way, is who this group is.

Katie: I also know that you write the Weekly Family . . .

A4: I do a Family Newsletter yeah; I can talk about that. This is something I started about five or six years ago when I got my computer, and it's a Sunday Newsletter that goes out to my grandmother's family and it reaches 78 email addresses in five continents at this time. It goes out to five continents and 78 email addresses, and it's a basic overview of the family, of the news. It keeps up with birthdays and anniversaries; it keeps up with the anniversaries of peoples' deaths, family websites, family news, different things. A different opening, a standard closing, different things that happen; so everybody's kept informed with such a large family. We are now 169 strong and about to have 170 next month in December. So it's just too hard to keep up with what this one is doing and what that one is doing, with so many generations. It was the right thing for to do and it still is.

Katie: What motivated you to do that?

A4: What motivated me to do it, is that one Saturday morning when I was at our congregation, our eldest Rabbi gave the sermon of some sort, which I don't remember the topic; but it got me thinking more about family and thinking this is what I need to do to keep our family connected. It just blossomed from there. It started out small and it just blossomed up to 78.

Katie: Why is family connection important to you?

A4: Well because my grandmother came from nine siblings, including herself, and we are a very large family and there is a lot of discord, a lot of exclusions, so to

Speak, in the family, if you will. I'm not sure that's the right word, but this one isn't friendly with that one, or this one isn't that; and I feel that I'm like the glue that keeps everyone together, whether they are on a social basis with another family or not. We're all connected by this one newsletter, whether everyone is connected outside of the newsletter. At least the newsletter keeps everyone informed, connected, and keeps us together as a family, since we're so large.

Katie: Are you saying that some people that don't talk to each other may receive the email?

A4: They do, and even if they're not on a social basis with another member with the family, at least there's a connection because of this newsletter. That we're all connected whether we want to feel the connection or not, I feel the connection and I feel a togetherness because of this newsletter.

Katie: How did you come up with the idea of a newsletter once you heard the Rabbi's sermon?

A4: It just gave me an idea that I have to do this, and if I could remember more about what the newsletter was about, and it obviously dealt with family because that's why I decided to start this. It was just the right thing to do. As I said earlier it was the right thing to do at the right time, and it just evolved, even to an extended family as well. We have extended cousins who hear about the newsletter and say please include me and please include my family in the newsletter. It just evolved because everybody knows how important family is to me.

Katie: So that sounds like it's definitely been a theme for you, even in from the early days of the cooking, being connected to your grandma through the cooking and

participating and helping others connect. I know certainly in this day and age, not everyone feels that way. What do you think makes it so important to you?

A4: To feel that connection to family; let me think if I can come up with something new that I haven't touched upon. I think in general we've just been generally close as an immediate family, and I think that has a lot to do with it. All families are not close and I think our immediate has been, and I think that really plays a part in it when your family is close like that. Then you feel like you have more togetherness and more in common to do things, such as in my case, the cooking and the newsletter. And if you're not close with your family, it's important to keep traditions and to keep memories and stories and all that. To pass them on to the next generation so that they too can know the past and know about their history for future generations, so a family goes on even when the physical sense doesn't. The family still carries on through the next generation.

Katie: All right, well that makes sense. Well let's go back to the country music. A lot of your special interests start with a C I'm noticing; you have country music, community service, communication, cooking and bowling.

A4: Well bowling fits in.

Katie: Your bowling fits in. So tell me in terms of how, like when you started listening to country music and then when you were engaging in that special interest, what did it look like? How did you collect the music?

A4: I started with a paper in school, is my earlier remembrance, back around '82 or '83, somewhere in that range of time; and we were asked to name musical influences and country music was right there, plain as day, in some of the artists

that I saw as influences of the day. The way I really got more and more interested as time went on, there was a company called *Berkley Tours*, it's no longer in business, and they were running a tour international, a bus tour, and we had never been, my father and I so we said let's go and see what it's all about. We went that very first year and 21 years later, we've been going ever since. We liked it so much that we started going on our own and we just enjoyed it ever since.

Katie: Name a few of the songs that you remember being your early favorites?

A4: Well early artists I can name more artists per se than songs, but I remember writing people down like Kenny Rodgers, Dolly Parton, those people that were crossover country artists of the early 80's, and they were people that I really looked up to at the time. It just evolved into a love for the old-time classic country music.

Katie: You were pretty young when it started. How did you listen to the music or did you find it . . .

Art: Well something which I haven't really touched upon, but I have a tape collection that marvels most people's problems, since most people unfortunately have switched away from that, but I have a tape collection that is bigger than life. It's not all country music, but it's a lot of different forms of music. I have close to 950, if it isn't over; not quite 1000 yet, but I'm working on it, slowly but surely.

Katie: All of country music?

Art: No. All different forms of music, but my madness has it all where it's all categorized.

Katie: Oh, tell me about that.

Art: I have different boards where the tapes fit in, tape boards; and each group has its separate board. There's a board that has all the people who are *Opry* members for instance; the *Grand Ole Opry* in Nashville. There's a board that has all the members who are members; there's one where it has all the people who have performed at the *Grand Ole Opry* for the entire year. There's another board that has all the country music artists that are not members of the *Opry*; there's another one that has artists from the 50's and 60's; another board, which has artists from the 70's; then stuff that's more current like 90's and beyond. I have everything categorized.

Katie: All country music.

A4: No not all country music, all different forms of music--rock-n-roll, country music.

Katie: Is there a board for each genre?

A4: Yes, each group has different eras, different forms of music. I've got it all categorized and all alphabetical in each board. It's all done alphabetically per board. I'll show you that later on and we can understand it a little more in depth.

Katie: So sometimes it's by genre?

A4: It's by genre or decade. I basically got that interest when I was delivering newspapers back in the early 80's for the *Observer Eccentric*. They were giving prizes away for the amount of sales, or whatever it was. So I started collecting tapes from them; they were giving me free tapes for my work. I was winning prizes and I was getting tapes, and that's what started it over 25 years ago, was that and then it just grew from there; well over 900 today.

Katie: What kind of tapes did they initially give you?

A4: They were giving me tapes like *A Chorus Line* with what I remember getting from them; musicals and popular music of the day and different things like that.

Because you could win different prizes and I was choosing the tapes.

Katie: Oh, you got to choose which ones you wanted?

A4: Yeah I got to choose what I wanted and I was taking the tapes, and that's what started it. And that's part of the music.

Katie: So in the beginning you got tapes from winning these contests, then where did you start finding the music?

A4: I'd get them all over; I'd go to record stores. I'd go to different places that sell music and sell tapes predominantly. I'd look for deals. When *Harmony House* went out, I bought out a whole bunch of their collection of stuff, not even for the music; but because tapes were a little bit harder to find, I would throw the actual music out in cases, because it wasn't a music interest of mine, and I would use the jackets of the tape to replace jackets that were worn out or cracked. When the stores were closing, I would just buy out whatever their lot was for a ridiculous figure; and then most of the music I didn't keep. I kept the outer casing, which was in good condition and replaced outer casings that were in bad condition on the existing music. So I find them all over the place. When I had just returned from Nashville, the record store that I go to there had a huge special, which I took advantage of. You can find things all over the place. At flea markets I find a lot of stuff.

Katie: So finding almost tape covers has become . . .

A4: Tapes are going out of business yes, then it's an absolute must to buy out what they have so that I can replace and make things look brand new and increase the value since their open. They don't have mint value but at least they'll be at least in good condition with a brand new cover.

Katie: So what does it end up costing you a couple of cents per . . . ?

A4: Sometimes you can get things for, I've gotten things for a couple of cents--like I'll say "How much do you want for the whole lot that you have here at the counter?" "Oh give me this--will you take this? fine." They'll take whatever reasonable offer sometimes, just to get rid of it because they've got to close the store and there's nothing else they can do with it. They'll probably just take it to some pot hole somewhere that'll get thrown away so they might as well make something on it to me, who can appreciate it, than to throw them away.

Katie: Even though you end up throwing some of the music away.

A4: I throw away some of the insides, but I keep the outer jackets if it something that's not really of interest, correct.

Katie: So for the country music that's been around for quite a while; and is there any other--you said something about the *Grand Ole Opry*, say more about that.

A4: Well the *Grand Ole Opry* is the longest running radio show in American history; it's in its 82nd year. It just celebrated 83 years on its birthday. I go down to Nashville every year, and for the past 15 years, for their birthday celebration in October. It's their big birthday celebration that they do in October, and it's a real passion with me. I listen to the *Opry* just about every weekend off my computer. I'm able to pick it up on my computer. I'm able to get it on the radio as well from

Nashville, but not always as clear, so the computer tends to work better. And it has become a passion with me for well over 10 years that I've kept a log journal of every single show that has ever been done at least 10 years running or more, and I do a lot of statistical work with them.

Katie: Can you say more about that?

A4: Yeah. I keep notebooks and each week I put the lineup as it happens into the book, and I do a lot of statistical work--I keep a list of every artist by alphabetical listing of who performs. I keep a listing of every artist by numerical, how many weekends they perform during the year; a listing of every artist that's been on the portion that's been televised; every artist who's hosted a segment; different things like that. And really it doesn't have a purpose, but to me it does. If somebody asks me a question I can almost go back and look it up and have the answer for them almost instantly. If they say when did so and so make their debut, I know it was around this time. I can just go look it up, and there it is right in my records. So to somebody else it may seem meaningless and it's sometimes a lot of work, but I think it's worth every effort. Plus I keep the actual lineup that I copy off the computer in a notebook, so I go back every 10 years with every single lineup that's ever been for over that time.

Katie: So A4, are you saying what motivates you to do this, is just in case someone may have a question?

A4: Not necessarily just because of a question, it's just my love for music and my love for the *Opry*; and it's just become a passion with me to want to keep all that information because I love statistics. Statistics are figures. I don't understand

numbers per se in business. Business I have no clue anything about numbers; but when it comes to things like this I really like the idea of saying, oh we've seen this one this many times, or this one has performed that many times, and this or that. It just fascinates me to know all that information, because country music is one of my passions obviously, so I just enjoy doing it.

Katie: When you talk to other people about your passions and you tell them the kind of detail that you go in to, what do you feel are their responses to it?

A4: Not a lot of my friends know into what detail I, I mean my girlfriend obviously does, my parents do to some extent. But not a lot of people do, and know exactly to how much trouble I go through every week to keep a record of each show that transpires; and sometimes when I have to call down, let's say I call down to Nashville for instance, to get some information. I have to explain to them what I do and it's not like I'm doing anything wrong obviously by it; it's not like this has anything to do with copyright laws obviously, but they're not upset by anything I do obviously. They're just not aware of my records obviously, and how extensive I go when I have to ask a question about something.

Katie: What have your parents said to you when they've found out how much time and energy . . . ?

A4: At one point, they wanted me to do it on the computer, but I haven't really gotten to that. I prefer the notebook personally; I don't know if it's easier or not, but for me it just seems to work better, versus trying to figure out how to set up a system on the computer. Then I would have to transfer all this, and to do that, you couldn't do it. All those years of writing could never be transferred, at least not

for me. It would take way too long and, you'd need every hour of every day for a couple of years to do that, and that's not an issue. They understand what I do and it's record purposes. Like Dad will ask me a question and I can tell him based on the number of times we've gone and lists we've seen or who we haven't seen.

Katie: How would you describe their reaction?

A4: I don't know if they really have a reaction per se. It's not that they're encouraging me or discouraging me to do this or not do it, or whatever. They really don't have a reaction, and it's more for my benefit than anyone. The way my memory works or doesn't work, in most cases because my memory sometimes, and I'm not old enough to say that, but sometimes my memory doesn't serve as well as it should. So here I've got all these recordings down of all the shows, so it helps my memory as well because then I don't have to guess on anything. I have all the stuff so if my memory fails me I can just go back and look and sure enough, I remind myself oh, okay.

Katie: And this started 10 years ago?

A4: At least 10 years ago. I don't have the exact date in front of me when it all started, but my records go back at least to '97; complete records. I started records a lot earlier than that but complete records.

Katie: What kind of records did you do before that?

A4: The same thing--just not as complete, because when I wasn't able to fully listen, when I would go away for the summers and I wasn't home the whole year, then it was much harder for me to keep records obviously, and because I only had the

radio to work with. The national station only comes in when it's dark because of its signal, and it was harder for me to keep good records.

Katie: Oh, so you had started this when?

A4: I probably started it in the early 90's somewhere, so probably at least 15 years ago. But because of the technologies of the day with only the radio, and only being able to get it at night, it didn't allow me to keep very good records. because in the summer the days are obviously longer, so I have less time to listen, and in the winter the days are shorter, so I'd have more time to listen.

Katie: How do you think technology has impacted your experience of your special interests?

A4: Computers have done wonders for it, because the computer has allowed me to at least with the country music, allowed me to listen to the *Opry* every single weekend, and when I can't listen, it allows me to utilize their archive services when they're available and recorded, to listen so it's really, really, changed the way things go. At one point and it's eased up a little bit, at one point the *Opry* ruled my life basically.

Katie: Say more about that?

A4: It was a Friday night or a Saturday night, and if anything was going on, the *Opry* was the only thing that mattered; and people knew if they scheduled something don't look to see me, because that was really my passion and because I didn't have the advent of a computer back then. It was very hard for me to listen to the program; if I didn't hear it I was out of luck.

Katie: What if people wanted to listen to it with you?

A4: That's fine, but if people scheduled a party, let's use as an example; they knew that I probably would not show up, because the *Opry* was my first and foremost love and still is my first and foremost love. Now with the advent of computers, and now with the advent of other things, it's allowed me to free my schedule up a little more and be a little more lenient in my activities. So even if I can't be home to listen to it first time around, then hopefully the archives work and I can listen to it at a later time when they go up. So it's kind of freed me up and people got to the point where people knew they were honored if I showed up at something on a Saturday night because they knew what I was giving up to do it.

Katie: So the *Opry* plays Friday and Saturday?

A4: It plays Friday night, Saturday, and between March and December, it plays on Tuesdays, correct. During the higher tourist seasons they have a Tuesday matinee to accommodate the weekday tourists through the Christmas season.

Katie: So technology really sounds like it has freed you up so you're not . . .

A4: It has freed me up some. I'm still very passionate about it obviously, and as often and if it's at all possible, I'm gonna be there to listen to it, first run. But it has allowed me a little more flexibility with the archival work that they do.

Katie: Are you aware of anything that happens, like I don't know, if there are opening credits or as the show begins, are you aware of anything in your body like excitement or anything that happens, like when a show comes on and you start to listen to it?

A4: Well if you're familiar with country music, one of the big things with the *Opry* and has lasted through the test of time, is square dancing. Square dancing has

been a big part of country music for as long as country music has been around. In the dance halls, in the mountains and the hills, the one thing that starts is, they always start with the square dancers. They come out and I've been known in times, and my girlfriend will attest, that when they come out, I've been known to go along with them. Not that I'm really good with square dancing, but I've been known to do that with them.

Katie: You got up on stage?

A4: Not on stage, but at home. I kind of do moves and I've been known to do that on occasion. Not always, but I have been known.

Katie: Is it the same dance every opening?

A4: With them, usually, but different through a different instrumental; or a different musical number.

Katie: So you could actually learn the dance and just do it.

A4: I don't know if I could learn the dance and do it, because I'm not doing necessarily what they're doing. I'm doing as if I was them, just for the excitement level, because it's always exciting when the show starts and keeps going.

Katie: Are you aware of any kind of thing that happens in your body throughout the course of the show?

A4: Whooping and hollering, for instance. It's excitement, my girlfriend does as well and everybody does. It's energetic music, it's true life music, and you just have to use the mating calls, so to speak, of the artist or the musical form, if you will.

Katie: As you listen, you're also keeping all these records. What room does this take place in?

A4: My computer's in my bedroom so it usually happens upstairs.

Katie: And then are you sitting, are you standing?

A4: I'm at my desk, because that's where the computer is, and I keep my logs.

Katie: So would you say you're sitting?

A4: I'm sitting, but I'm not the type of person that actually sits per se, for very long. I have a very short attention span, in terms of sitting. I can't do one thing very long. I have to do 20 things.

Katie: Okay so you sit for a minute.

A4: I may sit for a while and then get up; I'll eat something, I'll whatever; it just depends. If my girlfriend is there and we're doing something else, or whatever is going on that evening, while we're listening . . .

Katie: Oh, so you can do other things while you're listening?

A4: Oh yeah. I can do 20 things while I'm listening at different times. I'll be doing one thing, then I'll do another thing, then I'll do another thing and go back to that thing.

Katie: Was it the same before the computer?

A4: Yes and no, because you can play games on your computer. You can do this and that while you're listening, and do other things.

Katie: No, but before, when you just could listen to it on the radio?

A4: The same excitement level, oh yeah. If I left the room, I'd just turn the radio up louder so I could hear it in a different room. And you could watch an hour of it on television and different things. It's just a high level energy really. You can listen to it as many times as you listen to it, but there's actually nothing like being in the

audience when the curtain goes up, and seeing it done live, and seeing all those people you listen to every week right there in front of you. It's just the greatest feeling in the world, and then you get to meet some of them. It's just the greatest feeling in the world.

Katie: Describe the feeling.

A4: Describe the feeling? It's really like none other. Here you are actually seeing the people and hearing the songs that you listen to all your life, as long as you can remember, right there down in front of you, by artists who have been around a lot longer than you have. And there they are and they're doing the music and it's just the greatest feeling in the world. A lot of my friends who have never been down there, they know they can look to me for the answers of what to do, and where to go, and who to see, and all this stuff because they've never gone, and once they've gone their hooked. Every single person who has gone, has been hooked in that city and that program, and some of them talk it up as well, because they say don't knock it until you've been there. It's the greatest place; everybody knows that once you're there, you're smitten. I would tell anyone to get down there.

Katie: I was there once.

A4: Yeah, I would tell anybody who's never been it's a must; and once you go you'll almost want to go anywhere else, especially if you like country music, or any form of country music.

Katie: So this is very interesting. Talk a little bit if you would about some of the other interests, about like the game shows, soap operas and old television.

A4: Well, I've always had the theory that if something isn't broken don't fix it, so if you've got a good thing such as a classic television show, a great game show, why improve on what can't be improved upon; and this is stuff is so great and it was so entertaining that there's just such a love for it and a passion for it. There's a show that comes here, this year it was only once, but sometimes we get it twice a year. It's a comic and collectible show that comes every year, and one of the features is that they're bringing the old classic TV stars to the show so you can meet them, you can get autographs from them and they do charge. Some of them are not cheap, because this is their only form of income since not all of them work currently; but it's just a love for getting to meet and see the people that you've watched growing up. You've watched all these great programs growing up and now you're getting the opportunity to get to see them and to meet them and to get them to sign a book that you may have, or a tape that you have, or a memorabilia piece you have, telling them how much they meant to you and their show meant to you growing up.

Katie: Can you give me an example of that?

A4: Well I've got an autograph book of pictures, and pictures of me with other people that will just probably rival anybody's in all entertainment forms. One of my other interests is autograph collecting, and I go to the shows and I meet the people that have influenced me, whether it be classic television, country music, game shows, any of that sort of thing; soap operas. I just enjoy meeting them and getting to be around the people that made us laugh and be entertained on a weekly basis, or in soap operas or game shows on a daily basis, for that matter. It's just a love of

mine. I collect synopsis books from the television shows, all the different shows that have books out, which has all the program guides and episode guides and cast files and all that sort of stuff. It's just a hobby of mine, and a lot of my friends too. We just enjoy it.

Katie: What do you do when you get together with your friends; do you talk about this stuff?

A4: Oh, a lot of times. Oh yeah, because most of my friends are country music related. They're big into country music so they like all forms of it. They like newer, older, different things. They're like me; we like the music, but we like to meet the artists and become real good friends.

Katie: Where did you meet the people that are also into country music?

A4: Some of them I met in Nashville from all over the country; some of them I met here, going to what's called the downtown Hoe Down which takes place the weekend after Mother's Day in May. It's a great time and a couple of people I met down there and became friends with; some I met in Nashville over the years and we've become very good friends; you meet them all over the place. You can go to shows and you're with somebody enough that you just start talking, one thing leads to another, you become friends and you're doing other things. We go have dinner; we might acknowledge a birthday, different things like that; email, all different things.

Katie: That's another way the computer too gives you a different way to keep in touch with people.

A4: Oh yeah especially all over the country obviously, and the world; my family and friends, and if you've got family in a different continent, you don't have to use the phone card or pick up the phone. You can just instant message with them, you can email, now they have voice mail, which I haven't done through the computer, but you can actually use--it's like picking up the telephone and talk to them on the computer. There's all different ways of quick communication with your computer and you keep in touch and keep your passions and loves.

Katie: So would you describe, like at least the country music as an entrée into the social world?

A4: It's helped, immensely.

Katie: Even though there have been times where your special interests also prohibited you from going to special events because . . .

A4: Well yeah, but I've made more of my friends that I have today through the country music world than I would say, anything else. That's where I probably made 99% of my friend base, is through country music and through our interest.

Katie: Okay, so finding people with common interests.

A4: Exactly. The people that I met over the years based in the country music field outside of our congregational life, have allowed me to have more friends than I probably would have ever had if it weren't for this interest.

Katie: Well when you initially, because this has been an interest of yours for a long time, when you first began this interest, did you think it was also an entrée into social activity, or was that more recent?

A4: Well I don't know. I've known a lot of these people for quite a while, so I can't say if I was thinking in net mode when I first started, probably not. I probably wasn't thinking about it as a social opportunity with other people. I was just thinking about it as a love of mine, and one thing lead to another, and you meet people and you become friends, and one thing leads to another.

Katie: You said initially that your interest started when you were going to write a paper for school.

A4: Yeah it was an assignment for school, correct.

Katie: Did you find yourself thinking about the *Grand Ole Opry* or country music during school?

A4: I didn't have so much knowledge of the music business at the time, I just knew of some of the people that I liked and had to, at the spur of the moment, put down these names in country music, but I didn't really know a lot about the *Opry* per se at the time. It wasn't until *Berkley Tours* offered that package when we went in 1986 that I kind of really learned more.

Katie: And by that time you were almost done with school?

A4: By that time, I was a year away from finishing high school correct; and that's when I started to learn and understand more of the music business in the country music world. I really didn't know a lot about it when I first started. I knew some of the music obviously. but that's about as much as I knew after that time.

Katie: Did you want to say anything more about how you engaged in your special interest around the game shows or the soap operas?

A4: Well I don't know. I've always enjoyed game shows and I always like to see people win things, and it's always exciting when you get to see somebody play a game and win a prize. I've had some minor dealings with game shows, actually my whole family has, but we were in the audience of *Price is Right* and when Bob Barker hosted, we were his special guests one episode.

Katie: How did you get there?

A4: A cousin of mine. Well at the time she knew one of the prize buyers who was the father of one of her day school students. She worked at the Jewish Center out in California and one of her kids, their father, was a buyer on the *Price is Right*. So when we went out there for whatever occasion; he did her a favor and got us special seats as Bob's VIP's. We couldn't try out for the show because we were his special guests, so we didn't have that opportunity; but we were fairly close up and we were supposed to meet Bob and we didn't. There was an issue at the end that didn't allow us to meet him.

Katie: Did you ever get an autograph from him?

A4: I think we got an autograph that was pre-stamped, but I didn't get to fully meet him at the time. Something happened, there was a glitch and we couldn't, but a lot of my family has been on shows with my cousin, and I know you probably know about that; and my aunt and uncle, back in the black and white days, were in an audience and they tried out. My grandmother tried out for *Price is Right* back in the black and white days, my aunt was on Jeopardy, different things. We've had a lot of game show connections. I've always just loved them and they're fun to watch, just good entertainment.

Katie: Do you archive those?

A4: I don't archive them and I do sometimes tape them; like they had the 50 greatest game shows of all time recently, so I did tape those. I'll tape special things, but I don't have necessarily archives per se.

Katie: Nothing like the country music.

A4: No, because what they did was, because taping was limited, they would tape over certain programs and re-use the tapes so a lot of the game shows the archives are long erased.

Katie: Who are they?

A4: The programmers or whoever; the people behind the scenes at the game shows. They would tape tapes not knowing what the value would be today, and they would tape over other game shows from the past. Not all game shows are available to the market anymore because they're erased. There may be highlights and clips that were salvaged, but some shows are just totally erased outside what we have in our memories of watching them. They just don't have the shows any longer.

Katie: And what about the soap operas; when did you get hooked on those?

A4: Soap operas I've been watching over 25 years; *General Hospital* is the one I watch. On and off I've been watching them over 25 years or more. I just enjoy it. It's just quality afternoon entertainment; comes on at 2:00 and it's good entertainment really, to watch the story lines. It's reality in a way, but not necessarily our reality, because a lot of the plots are twisted; but it's a lot of what

we see in real life. A lot of the story lines are really reminiscent of real life activities that people go through.

Katie: Are there any of the story lines you related to more than others?

A4: Not me personally, because they deal with a lot of heavy issues in a lot of cases, illnesses and maybe rape, or whatever the storylines may be at the time; but it's just an escape really into another world. You're watching these characters and it's just a fun escape I think.

Katie: Did you start that with somebody or did you know anyone else that was watching it?

A4: I knew people that were watching it, but I don't know if that necessarily got me involved, maybe it did; but I know others who were watching it and watching it religiously. My mother watched it religiously in those days, back in the day, but she hasn't watched in a while.

Katie: Did you use to watch with your mom?

A4: I don't know if I watched with my mother or not, but she knew as much of the storylines as I did back in those days, but now I know more because I'm still watching it.

Katie: Would you converse about it?

A4: We might, I'm not sure, but we may have talked about it; what happened here, what happened there, who did this to whom.

Katie: And you could keep her up-to-date?

A4: I guess and I would after she kind of stopped watching it. I would say, oh this happened and this happened, and she was kind of out of the loop, so it really didn't mean much after a certain while.

Katie: But she used to be a fan?

A4: She used to be, oh yeah, when most people were watching in those days, because most people had more time to watch.

Katie: Yeah, yeah that's true in those old days.

A4: Exactly when housewives were home and they had more time to look at these programs while they did their cleaning.

Katie: Oh, you were saying about the old television shows. What were some of your favorites and why?

A4: Oh, I had many favorites. *The Courtship of Eddie's Father* is my all time favorite comedy show of all time.

Katie: What do you like about it?

A4: It's just a wholesome family show. It only lasted three seasons and it was just a great show. There was a great cast, a great show, and *The Waltons* would have been my favorite drama. Another wholesome family drama set in the depression era, and it just shows you that no matter how things get, family can always hold things together. It's not all about the money, it's not all about the material things, it's about the family; and family, no matter how tough things can go sometimes, family will get you through it. Just keep a little faith in your family and you can get through almost anything. Sure money does help, but that particular show showed you week in and week out, that money isn't always the answer. With the

love of your family and your faith, you can get through almost anything. So those are my two all time favorite shows that I've always loved.

Katie: You used the word wholesome to describe most of them. What does wholesome mean to you?

A4: I think wholesome means a lot about good family values, good moral storylines, just family entertainment, something you'd want to watch with the entire family and you feel good about watching it because you know it might teach a lesson. It's just fun entertainment; it's just an escape from the everyday world and you're just sitting there laughing and watching these characters go about, just like a normal family would, or normal people would. It's just enjoyable really.

Katie: No matter how bad things get.

A4: Yeah, no matter how bad anything could be in your real world; you know that just turning on the television it's going to give you an escape from that into something enjoyable.

Katie: Can you give an example where something let's say bad happened during the day and then you kind of . . .

A4: You can have a bad day at work for example. Things can be going just horrible, you're just so upset and you come home and you put on a program and you just forget about all of that. You can forget about anything else and you're just so engrossed in that show, that that's all that matters. I mean sure you're not gonna totally forget what happened, but it's gonna give you that time, and I don't know if you want to say a cool-down period necessarily; but it's just a time to escape from anything else that matters and to be drawn into that world of those characters

and those actors that they're putting across the screen, something that's so believable to you.

Katie: What happened if like you've had a bad day at work and you get to watch *The Courtship of Eddie's Father* and all of a sudden the phone rings or someone interrupts your time?

A4: Certain programs that I watch, I've seen probably every single episode there ever was a zillion times. It's not the worse thing; unless it's one of my all-time favorite episodes, but I'll kind of make sure I do two things at once where I'll get the phone for instance, or I'll have the phone with me so I can listen and watch at the same time. I'll listen to what they're saying, but keep my attention span on the TV or the computer, or whatever it may be.

Katie: What's the other thing; you said you do two things usually?

A4: Yeah, listening on the phone and watching the television.

Katie: What about when you were living at home and your mom came downstairs and she said "A4 I need to watch my program now."

A4: I don't know if that would ever happen. We were never in that stage where we were fighting over a television. Sometimes they would say I want to watch this in this room and I'm like okay I'll go in another room. I'm not happy about it, but I'll go in a different room. Like if I'm in their house and they say "Well we don't really want to watch this." Okay fine I'll go in another room and watch by myself. I'm not saying I'm happy about it, but it's not my house so I guess I don't really have a whole lot of say in the matter.

Katie: So you don't remember having kind of meltdowns or . . .

A4: Not really, not really.

Katie: Did you experience those meltdown tantrums in any fashion that you remember growing up?

A4: Oh I'm sure there were times, because I'm always the type of person that has to have their way; and if I don't get my way in any situation I just don't take it very well.

Katie: Like give me an example.

A4: I don't want to say I'm a poor loser because I'm not a poor loser, but if things don't go the way I had hoped they would go, I get frustrated a lot and I just don't take change very well.

Katie: What do you do? What does it look like?

A4: What does it look like? Well it's not always pretty. What does it look like? It's hard to say, because if things aren't going the way I want them to go, sometimes I'm like okay, there's nothing I can do about it and I'm just going to have to move on and make the best of the situation; and other times I just get frustrated. And I'm like, okay if this is gonna be this time of day, then maybe I'll just give it up, but I never do. I always carry on, as bad as things get.

Katie: When you "say give it up" what does that mean?

A4: Meaning sometimes that you might get so frustrated at work because you're having a bad day for instance; things are not going the way they should and it's not always your fault. Some things stem from other reasons and you get to the point, is it really worth it? What I'm doing every single day, is it really worth all

this aggravation or frustration? But you just carry on. If I didn't love doing what I'm doing, I wouldn't have been doing this for over 20 years.

Katie: So you're saying sometimes you think about quitting when you're having a bad day?

A4: It's all talk. I'd never really quit, because I'd never really know what else to do with my time because this is what I know. But sometimes you just talk; you just talk just to make conversation. That you're just so frustrated that some days you want to throw in the towel and say, hey if you can do a better job, you do it and leave me alone.

Katie: So when you get frustrated, tell me what A4 looks like frustrated?

A4: I'm not always pretty. I can get upset with people sometimes.

Katie: And when you get upset what do you do?

A4: I can use a few words that aren't really complimentary.

Katie: All right so maybe you swear a little bit?

A4: No, not necessarily swearing per se, but just in nicer ways of telling people off.

Katie: So there would be no doubt that they would know that you're upset?

A4: They'd know I'm upset and they know I'm never going to give in because I'm a very determined person and I will get things done and things will happen my way and that's just the way I am. I'm very determined and I don't give in to people. I'm like my mother; she's very outspoken and I'm very outspoken and we both get our way. We know how to get what we want and we don't give in to anybody.

Katie: So let's say for example the holidays are coming up and you were gonna make the dishes on the holiday dinner, and your mother said she wanted this, this, and this on the menu and you said "Absolutely not."

A4: Well I'm not saying anything, but we're so much alike. We're from one mold, but our ways are so similar and we always get what we want from people most of the time. That we're pretty much the same it's not like we're opposites per se.

Katie: So what would be an example of something that would happen where you wouldn't take no for an answer?

A4: Like for example, if you're in a store and your receipt is wrong and they're denying it and they're arguing with you and you're like "No it's this way," or a price in a store or whatever it may be; and you don't let up until it's rectified or if you don't feel something is the way it should be. We don't let up until we've gotten the satisfaction we feel we deserve.

Katie: Can that be problematic with your girlfriend?

A4: Well she's not as assertive as I am per se, or forceful. She's gonna let be whatever is gonna be and we're the type of people that we want what's coming to us. We're not looking to get something for nothing but we want to get what we're entitled to and we're entitled to that; and if something isn't right we're gonna make it right. We were out last night and there was a problem with our meal and I wasn't going to ask for anything for nothing, but I just pointed out the problem, they showed the manager and the manager came over and said we'll take it off your bill. We weren't suggesting anything; we were hoping the right thing would be done, but we weren't asking and it was rectified and that's all we ask. Just get it rectified,

do it right and we'll get what we want. If we're not happy about something, we want it taken care off. I mean anybody would want that, I would think. That's not unusual; we just happen to get things more often than most.

Katie: I'm struck when we're sitting here talking at (a) how much confidence you have and, (b) that even though you kind of grew up with this learning disability, it doesn't sound like it's kind of deterred you.

A4: No, I've always known what my goals were and I've stayed with them when others have doubted my goals. In college I was doubted. They tried to sway me away from cooking.

Katie: Where did you go to college?

A4: Oakland Community College.

Katie: Were you in their cooking program?

A4: Yes I was in their Culinary Arts program and everybody tried to sway me away from that. They said no, no, no, go with your second choice.

Katie: What was your second choice?

A4: Well I had also thought about going into some form of media. like television or something, production or who knows what. And they said maybe you should do that, and I said no, this is what I want to do. And sure enough, this is what I've done and I've proved them all wrong; and I said I can do this.

Katie: Who doubted you?

A4: Oh my counselor, for one. He didn't think I could handle it. It was a special needs counselor and he didn't think it was gonna work out for me and other people and .

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Katie: Did your parents feel like you could do it?

A4: I think they knew that I could do whatever I wanted to do. I don't think they were necessarily doubting of it. They knew I would never be at the top of the field obviously, but if this is what I wanted to do, they weren't gonna stop me and they would stand by me to whatever extent it went, and I proved everybody wrong.

Katie: And has that been consistent throughout your life? That being?

A4: I think so. If I want to do something, they know I can do it. People know I can put my mind to do something and I'll get it done. It may take a little longer than most, just because of my attention span, but I'll get it done.

Katie: You said twice that you have a short attention span, yet you and I have been sitting here talking for over an hour and I haven't sensed . . .

A4: I do have a very short attention span when I'm by myself, because I don't keep attention to one thing very often. My mind tends to wander. I get bored very easily with things.

Katie: Did you want to say anything more about bowling because that's kind of a physical activity.

A4: I'm not great at it, but I do enjoy it. It's a Sunday morning meet with the guys. We enjoy it.

Katie: Who are the guys?

A4: It's through our congregation. It's through our Men's Club and they don't have to belong to the congregation, they just have to belong to the Men's Club and then pay their dues; and anybody can join the league. It's just something I've enjoyed

most of my life. It's a great sport, it's a family sport, an easy sport to just throw a ball down an alley and knock down some pins.

Katie: For some people.

A4: Hey you just throw it down the alley and hope for the best. That's all you can do, hope for the best. It's just an enjoyable thing; it's good exercise and it's something I enjoy. There's not a lot of thinking that's involved with it.

Katie: You know too, some people who are diagnosed with Asperger's Syndrome have fine or gross motor challenges, yet you're a chef so you have to be good at fine motor.

A4: Exactly.

Katie: And you're a good bowler. Do you have any challenges with gross or fine motor?

A4: That I'm not sure. I'm not real clear on that, so I don't know.

Katie: Do you remember things being, like you had mentioned that even though you watch the square dancing portion of the *Grand Ole Opry* . . .

A4: I don't know the moves like they're doing it. I make my own moves up and do it to the music.

Katie: But when you go to a Hoe Down, do you follow the square dancing?

A4: Well, I may be able to. We did learn it in school, back in the day. They did teach that in music class, but probably not, since I'm not versed; I've never been trained in dancing, so I would probably have to be classically trained to know the finer steps; but to make your own moves it isn't difficult to make your own moves.

Katie: But even when there's just a caller and they . . .

A4: Well, I don't actually go to those types of things. Outside of the *Opry* and country music shows, that's about as far as it goes right now.

Katie: So square dancing never really became part of the interest?

A4: I never really went to dance halls and that sort of stuff. No, I really haven't gotten in to that.

Katie: So is there anything I didn't ask you that you feel like is important to add?

A4: I don't know, we've touched on quite a bit and you've done a great job for whoever is listening. She has done a great job and she deserves a good grade on this paper, not that I'm biased, but she deserves a good grade on this paper.

Katie: You're very encouraging.

A4: Yeah, but not that I can think of. I think that you've asked all the good questions. You've done what you came here to do as far as I can tell.

Katie: All right thank you.

[End of Interview]