

FINDING PLACE IN A “NEUROTYPICAL” SOCIETY: A PHENOMENOLOGICAL STUDY  
OF INDIVIDUALS WITH ASPERGER’S SYNDROME

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(ABSTRACT)

In 1944 Hans Asperger, a Viennese physician, identified a neurological disorder which hinders a person’s ability to communicate and interact socially. Lorna Wing’s research reintroduced the disorder in 1981, but Asperger’s Syndrome was not recognized in the United States until 1994. This study, aimed at generating knowledge about the lived experience of individuals with Asperger’s, is grounded in hermeneutic phenomenology. The writings of Martin Heidegger (1962, 1971), Hans Gadamer (1975/2003), and Edward Casey (1993) provided the philosophical foundation that helped me to open up the phenomenon as I answered the question, “What is the lived-experience of individuals with Asperger’s Syndrome?” Van Manen’s (2003) six research activities served as a framework: (a) turning to a phenomenon which seriously interests us and commits us to the world; (b) investigating the experience as we live it rather than as we conceptualize it; (c) reflecting on the essential themes which characterize the phenomenon; (d) describing the phenomenon through the art of writing and rewriting; (e) maintaining a strong and oriented pedagogical relation to the phenomenon; and (f) balancing the research context by considering parts and whole.

Individuals with “Asperger’s Syndrome” navigate the world in a manner that makes sense to them. These adults desire to build nearness in what has been coined a neurotypical world. Five adults with Asperger’s Syndrome were interviewed three times each, sharing their experiences in school, the workplace, and community, elaborating upon how they attempted to fit in with their neurotypical peers. They also shared strategies developed to build nearness and find place in the neurotypical society. Participants reported experiences such as wearing masks as a tool to gain insider status in the neurotypical world, and the sense of exhaustion this behavior involves. They described their experiences with terms such as “bully magnet” and “emotional traffic jam,” in illuminating the daily discomforts they face attempting to meet the expectations of social interaction. The experience of bullying particularly seems to have had a lifelong impact.

Recommendations for further research include examining the effect of early diagnosis, and how early transition experiences contribute to social development. A study on the effects of bullying that Aspies encountered during their school years would also add valuable information to the literature. Finally, work is a significant part of every adult's life. Recommendations for employers include exploring mentoring or natural supports to employees who disclose the disorder. Additional supports and resources would increase performance and job retention.

## DEDICATION

I want to dedicate this study to my children Naisha and Lynn, Jr. for your support during my journey. You have been so patient over the years while I pursued my educational goals. You have been great cheerleaders and kept me grounded during the process. We had a devastating 2005 year with the sudden loss of your father. However, we have remained strong. You are the loves of my life. Thank you for the grandchildren Khaliq, Jr. and Marlyn, the new loves of my life.

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## PREFACE

The phenomenon that I have chosen to study for this dissertation relates to the lived experiences of individuals with Asperger's Syndrome. In 1944, Asperger began his study of four young male patients who exhibited autistic psychopathy.

Asperger clearly cared about these children who in most people's eyes were simply obnoxious brats. They were very unchildlike children. They did not fit in anywhere and were troublesome because they lacked any respect for authority. They made their parents' lives miserable and drove their teachers to despair. So unappealing were these strange boys that other children and adults were drawn to ridicule them. That a young doctor was captivated by these difficult children was a miracle. Asperger appreciated their surprising positive features while fully recognizing their negative ones. He admired their independent thinking and capacity for special achievements, but also candidly documented their learning problems and seemingly spiteful and malicious behaviour. (Frith, 1991, p. 7)

Since that time, more research has been conducted on what has become known as Asperger's Syndrome.

The study of Asperger's Syndrome is still new in the United States. The incidence of children and youth identified and reported as having the syndrome has increased over the past fifteen years and has gained the attention of professionals in the medical and educational fields. The characteristics of this syndrome have been both puzzling and frustrating to families who live with an individual with this disorder. Parents may be concerned that their child will never be able to say the words "I love you." The research continues and the hope for a cure is at the top of every parent's list.

A large amount of literature is available about the autism spectrum, which links Asperger's to autism (Autism-Asperger). The literature reviewed revealed publications mostly related to the study of children with Asperger's Syndrome including epidemiology of Asperger's Syndrome, social skill interventions, causes, theory of mind, diagnoses and misdiagnoses, and medication management of children and adolescents within the school and the community. However, as the children and youth grow up to become young adults and engage in adult activities, the literature is not as abundant pertaining to their lived experiences especially in reference to social and employment experiences. In fact, only a limited amount of literature is

available in the area of the lived experiences of adults with Asperger's Syndrome as further discussed in Chapter Two, along with contributions of this study to the literature base.

This study has its grounding in hermeneutic phenomenology. Van Manen (2003) writes, "Hermeneutics and phenomenology are human science approaches which are rooted in philosophy; they are philosophic and reflective disciplines" (p. 7). The two approaches being used to provide the reader with a clear view into the experiences that many individuals face daily, as well as an opportunity to reflect on these experiences and gain an understanding of what it is like to live with Asperger's Syndrome. Since no two experiences are the same, it is important to show the reader the experiences as they reveal themselves in school, the work environment, and in the community. The philosophers that connect to this study allow me to open up the phenomenon of Asperger's Syndrome through inquiry and reflection to reveal the essence of their experience. Van Manen

(2003) notes, "To do phenomenological research is to question something phenomenologically and, also, to be addressed by the question of what something is "really" like. What is the nature of this lived experience?" (p. 42). I will wander and question as I journey through the chapters to determine what the experience of people with Asperger's Syndrome is really like.

Van Manen (2003) developed six research activities that I used as a methodological framework to guide this study. The six research activities, discussed further in Chapter Three, include:

1. turning to a phenomenon which seriously interests us and commits us to the world;
2. investigating the experience as we live it rather than as we conceptualize it;
3. reflecting on the essential themes which characterize the phenomenon;
4. describing the phenomenon through the art of writing and rewriting;
5. maintaining a strong and oriented pedagogical relation to the phenomenon;
6. balancing the research context by considering parts and whole. (van Manen, 2003, pp. 30-31)

In Chapter One, I share what oriented me to the phenomenon of Asperger's Syndrome. I explore the context of the relationship to my own professional experiences by sharing my early teaching experiences that were pertinent in my commitment to people who live with Asperger's Syndrome. In Chapter Two, through the review of various sources, I provide a context of what has been explored with regard to the lived experiences of people with Asperger's Syndrome

through various sources, including, but not limited to, literature as a backdrop. That backdrop includes movies, art, poetry, phenomenological literature, and other sources. In Chapter Three, I discuss the philosophical grounding, the philosophers that connect to the phenomenon, and the methodological framework of the study. The Chapter provides the philosophic grounding to support the methodology. Chapter Four reveals the lived experiences of people with Asperger's Syndrome through conversations and written reflections. I reflect on both the written experiences and those shared in conversation to discern emerging themes and make sense of the experiences. In Chapter Five, I bring the parts together in a written narrative to reveal the lived experiences of people with Asperger's Syndrome, and provide pedagogical insights for what might be done to help such individuals lead more meaningful lives—in the context of school, work, family, and the community.

CHAPTER ONE:  
RIDING THE EMOTIONAL ROLLER COASTER: TURNING TO THE PHENOMENON OF  
LIVING WITH ASPERGER'S SYNDROME

The Face of Asperger's Syndrome

"My Greatest Fear is Myself"

My greatest fear is myself.  
Control is not absolute: a constant struggle to maintain  
it drains my strength.  
I am always tired: I never get enough sleep.  
Events beyond my control happen around me: I do  
things that scare me. If I'm confused or angry or tired,  
I slip up and the body takes over.  
Watching your life like a void is scary. It takes an  
effort of will to take control again and just let it  
happen.  
I'm afraid of what I feel. Emotion weakens my control,  
making its grip easier to break.  
When I think, I sometimes think of letting go, just  
letting it all slip away. It hurts fighting all the time.  
I just want peace and rest.  
(Woodhouse, as cited in Attwood, 1998, pp. 160-61)

This poem speaks to the emotions and fears of a person with Asperger's Syndrome (AS), also called Asperger Disorder, High Functioning Autism, or Autism Spectrum, which is a neurological disorder that impairs a person's communication and social skills (Ehlers & Gillberg, 1993). Woodhouse, the author of the poem, writes about his difficulty understanding abstract concepts, his fears of not maintaining control in his life, and his fears of just being.

How did these fears develop? Is it possible that something happened at a social function or work setting that triggered this poem, such as being excluded from a social activity? What type of slip-up occurred to make his body take control? Does he see himself as his own enemy? When Woodhouse looks into the mirror, what images are reflected there? What words does he use to describe himself? I wonder what steps Woodhouse has taken to regain control and eliminate his fear of self. What would it be like to live with such fear?

As a Special Education teacher who works with students who have Asperger's Syndrome, I seek to understand what their experiences are like in school, the workplace, and the

community. What does it mean to struggle with a self that lives between different worlds? When one lives in a body that one fears, how does a person develop identity? In pursuit of these understandings, the question that drives my inquiry is: **What is the lived experience of persons with Asperger's Syndrome?**

My interest in Asperger's Syndrome was born out of observing the challenges students face in their daily activities among Neurotypicals (NTs). Neurotypicals is a term coined by people with Asperger's when speaking about people who do not have the disorder. Communication and developing friendships can be a struggle for this population throughout life. The inability to socialize according to the norms of society is often a barrier to being with others. Marks, Schrader, Longaker, and Levine (2000) note that "Adolescents with Asperger syndrome are particularly at risk, given the increasing social demands during this phase of development" (p. 4). I observe students with Asperger's Syndrome as they attempt to fit in with their peers. They flounder about the school in search of a friend. Sometimes, they find a place in the social world, but many times they continue to wander in search of place.

As I explore the literature, I am discovering that we know a good deal about the syndrome, and yet very little about the people who live with it daily. As discussed further in this chapter, Frith (1991) discusses theory of mind, which deals with a person's ability to conceptualize mental states. According to Frith, people with Asperger's cannot relate to mental states of others. I lost my husband in the school year of 2005. A student named Stanley stopped by my office the day after my loss occurred. The room was dark and the door was locked. Stanley proceeded to the office of a teacher he knew to find out my whereabouts. When he arrived at the teacher's office, she told him that my husband died suddenly the night before and that I would be out for a while. After Stanley heard the reason for my absence, he began to walk out of the office. As he approached the door, he turned and said, "It must have been stress: Mrs. Miles said he cheats at chess." The teacher told me that Stanley was looking for me and hesitated to share his words. As the teacher shared what Stanley said, she watched my expression very closely to determine my reaction. I told the teacher that I was not offended. I shared that Stanley told me earlier in the school year that he played chess. So, I asked him to share a few strategies with me. Stanley told me that he did not play with amateurs. I went on to tell him that I

used to play with my husband, and when he began to lose he tried to change the rules of the game.

Someone else may have taken Stanley's words as offensive. He remembered what I told him earlier. When I returned to school, Stanley stopped by my office and it was business as usual. He did not mention what happened. We continued to prepare for his transition to adulthood. The beat goes on.

Gray (1998) discusses social stories and comic strip conversations as a strategy to assist people with Asperger's in understanding non-verbal communication. She addresses this strategy for both children and adults. Howlin (2000) speaks to the difficulty in distinguishing between high-functioning autism and people with Asperger's. Some school districts use Asperger's Syndrome, while others may use Autism Spectrum Disorder during the eligibility process to determine appropriate services for students. Attwood (1998) focuses on social skill strategies for teachers and other professionals who work with students with Asperger's Syndrome. Frith (1991) discusses theory of mind, communication strategies, guides for parents, and the origin of the syndrome. Only a small amount of literature by Grandin (1995), Happe (1991), and others focus on a person's perspective of what it is like to live with Asperger's Syndrome. The literature does not reveal a deeper journey into the day-to-day lives. Their daily experiences will allow others to walk in their shoes. This led me in the direction to investigate what the experience is like to live with this syndrome.

The following experiences reveal some of the struggles of individuals with Asperger's Syndrome with whom I have had preliminary conversations. Each person is trying to find his or her place within the community. Pseudonyms are used to identify the individuals.

### *Emotional Traffic Jam*

Having Asperger's Syndrome is a pain in the "Butt." It's very annoying! I don't always know how to talk to people, and I always have mixed emotions. And I don't know. Those are basically it. But it's very annoying. Well, a lot of times, I like to have my mother talk for me because I don't always know what to say to people. And I'm twenty years old and that's very embarrassing to be twenty years old and not be able to communicate fully with people.

Getting my words together, my thoughts together so that it will come out and make sense. On the job, it wasn't easy. People would ask me things and I didn't know how to answer. And it wouldn't make sense. I do not have a problem talking about things if I know enough about, like music. If someone wants to talk to me about music, that will come out fine. But, if they want to talk to me about something I never heard of or mostly my feelings it is hard for me to talk about it. That ends up coming out weird because I have a lot of feelings. Having Asperger's Syndrome is like an emotional traffic jam. All these feelings and thoughts sometimes want to all come out at the same time and there isn't enough room for them to come out at the same time. By the time they come out, it doesn't make sense. (Karen)

Karen describes having Asperger's Syndrome as an emotional traffic jam. When I think about a traffic jam, I visualize vehicles standing still at an intersection with nowhere to go and no detour available. Is this what Karen means? Does having Asperger's Syndrome leave her with nowhere to go, no detour for her to take in life? Karen says that it is hard for her to talk about subjects that are unfamiliar to her, or when she talks, her words come out weird. What is it that is stuck? Does she fear that informing the speaker that she is not familiar with a particular subject will make her seem less intelligent? Is this when the emotional traffic jam occurs? What is this feeling of "being stuck" like?

### *Touch Me, Touch Me Not*

We live in the world of touch. Everything we do involves some kind of touching. What does a touch symbolize? When one feels sad, a touch may come in the form of a hug to bring comfort and uplift one's spirits. When one feels alone, touch may come in the form of a shoulder to lean on for support. Imagine a body that perceives a touch as an uncomfortable feeling. For example, an accidental bump from a person in line at the grocery store, or from a person standing at a crowded bus stop may cause continuous misunderstandings on a daily basis. Will the words "excuse me" be enough to satisfy an accidental touch?

It is through the bodily surface that I first engage the world. Only because my eyes and ears lie on the surface of my body are they capable of disclosing the events taking place around me. My hands, in order to explore and work upon the world, must extend outward

from my corporeal “extremities.” My expressive face can form a medium of communication only because it is available to the Other’s gaze. No organ concealed in the hidden depths of the body could actualize intersubjectivity in this way. It is thus necessary that our perceptual, motor, and communicative powers cluster at or near the body surface. This surface is where self meets what is other than self. (Leder, 1990, p. 11)

Grandin (1995) shares that being hugged is too much for her to handle. She writes, “I wanted to experience the good feeling of being hugged, but it was just too overwhelming. It was like a great all-engulfing tidal wave of stimulation, and I reacted like a wild animal. Being touched triggered flight; it flipped my circuit breaker. I was overloaded and would have to escape, often by jerking away suddenly” (p. 62). What does Grandin’s body communicate to those who touch her?

My body is the fabric into which all objects are woven, and it is, at least in relation to the perceived world, the general instrument of my ‘comprehension’. (Merleau-Ponty, 1945/2003, p. 273)

This quote from Merleau-Ponty speaks to the manner in which the body receives and makes sense of the world. Being unable to be hugged made Grandin seem untouchable. The sense of touch seems to unravel her to the point that she has to escape. In response to being touched, Grandin flees to a “squeeze box” she designed when the touch from others overwhelms her. The squeeze box allows Grandin to control the amount of pressure she desires. Our body communicates how we feel at any given moment by the way we react. Something as simple as a touch creates a response of acceptance or rejection. Grandin’s body rejects the sense of touch although she wants to experience the feeling. This is such a struggle for her. It seems impossible to avoid accidental contact in our daily interaction with people. Touch becomes a barrier to being with others.

Karen’s and Grandin’s experiences with having Asperger’s Syndrome have led to feelings of being overwhelmed with emotions, resulting in emotional traffic jams and flight. I am quickly reminded of the circuit breaker in my home. When overloaded by the use of too many appliances, or a sudden surge in power from a vicious storm, all power shuts down. The options

are to unplug some of the appliances and set the reset button or wait until after the storm and power has been restored. Until then, the reset button is useless. What are the warning signals before the power surges? How do they unplug their feelings or reset their buttons to restore calm? I wonder how long it takes to restore calm. Leder (1990) writes, “My actions are motivated and organized by outer-directed concern” (p. 19). Karen’s and Grandin’s actions appear to be motivated by the lack of knowing and a negative response to being touched in their attempt to communicate and interact with others.

### *The Outsider Stigma*

All right, what it’s like to have Asperger’s Syndrome is it is hard for me to get friends. Okay, people feel they can treat you any way they want to treat you. I mean in a way you feel kind of miserable when you have Autism. All right, for example, if one student asked if they could see the yearbook, they would show the whole class but leave me out. People just put you off. (Mark)

In the yearbook experience, Mark’s classmates passed him over when they shared a yearbook. Mark thinks that he is being treated unfairly and that he should have viewed the yearbook like the rest of his classmates. When he was not asked to sign the yearbook, he perceived that his peers did not accept him. This experience of feeling left out is one of many Mark may encounter. How will Mark handle future situations when others leave him out of activities?

Fitting into a social group is important for young people, especially during their adolescent years. Davies (1942/1999) writes, “School-age children define themselves as group members, not just as individual friends” (p. 308). Adolescents are in search of their identity and their place in society. Popularity is the name of the game. Fashion, sports, and being a well-known face among peers often increase one’s social life and self-esteem during this critical period of life. When peers like or perceive you as one of the group, you tend to be less susceptible to bullying and being left out of social activities. You dare not to be different. Instead, you choose to be a carbon copy. Like a puzzle piece, you fit right into place. Life is good!

Some students do not fit into their social group. They are marked as different among their peers. Their dress is usually not of the latest style; the activities they engage in may be considered “dorky” by peer standards, and they just do not fit into any social group. Of course, not all adolescents that do not “fit in” have Asperger’s. Yet, Mark did not fit into his peer group. He was left out of social activities. He dressed like the others, but he just could not penetrate the thick social circles among his peers. Mark still asks, why?

Imagine a student that does not fit into a social group and could not care less. Gillberg (1991) discusses an eighteen-year-old male (no name) with Asperger’s Syndrome who purposely isolates himself from others. He echoes what is said to him, hums before answering a question and continuously picks at his fingers. He does not have friends and does not seem to be concerned about it. His classmates and family friends consider him odd, but friendly. Yet, he participates in an acting troupe. Acting appears to be a match for this young man. I wonder what he is like on the stage. It is interesting that someone chooses to isolate himself from others, but is open to an interest that draws crowds, various temperature changes, bright lights, noise, and spotlights with all eyes on him. I wonder what kind of roles he plays.

Samuel is a former student who has autism. While in high school, he struggled to fit into his peer group. He, too, wore the latest fashions, but was unable to penetrate the thick social circles at school and in the community. He did not have any friends at school. One of Samuel’s difficulties with peers was the noise he made that resembled that of a monkey. He blurted out this sound at unexpected times making him stand out in class, the hallways, and the cafeteria. Sometimes Samuel would make this sound at the request of classmates, which made him an easy target for a few students to tease and exploit.

During the lunch period, Samuel sat at a table of faces he considered friendly. Once seated, he would make the monkey sounds. The students would jump from the table laughing at Samuel or block the chair so that he could not join them. Samuel willingly played this game. At times, they would charge him a fee to sit at the table. This became a profitable small business for a few students. He willingly paid a cover fee to be a part of the lunch group until a staff member put a stop to it. He paid to enter the circle of friendship rather than being left out. Samuel did not understand that friendship is free of charge. The lack of friends and the quest to fit in is shared by William:

I was unhappy there [school], well because, you know getting on with other people, I just couldn't relate to anyone and I couldn't, you know, form any type of friendship with anyone and I was never happy with the work that I was doing because I was never satisfied that it was perfect enough and I got really stressed over it. Um, so I didn't enjoy it because I got so stressed about it, I became so depressed that I couldn't take my GCSE's and didn't get any qualifications there. (William, as cited in Portway & Johnson, 2003, p. 438)

William shares his unhappy school experience. He was unable to connect with his peers and was dissatisfied with his performance. When it became too much for William to deal with, he walked away from it all.

No one was created for isolation. When we become isolated, we are prone to being damaged, our minds lose their flexibility and natural kindness; we become vulnerable to fear and negativity. The sense of belonging keeps you in balance amidst the inner and outer immensities. The ancient and eternal values of human life – truth, unity, goodness, justice, beauty, and love are all statements of true belongings; they are the also the secret intention and dream of human longing. (O'Donohue, 1999, p. xxii)

O'Donohue speaks about isolation as an unnatural experience for people. He notes that belonging helps one to maintain balance. Each student experienced isolation, but handled the situation differently. Samuel was willing to pay for friendship. Mark wants to be one of the guys. He protests about the unfair treatment from his peers. The young man Gillberg speaks of his choice to be isolated from others. I wonder if he found his place in acting. William became so overwhelmed by the academic expectations he placed on himself and his inability to relate to his peers that he gave up trying. Each of these young men was in some way an outsider. Will they continue to exist as outsiders? They attempted to peel the thick layers of the social circle hoping to enjoy the sweet taste of belonging.

### *Lines of Misunderstandings*

The inability to communicate is a big issue for people with Asperger's Syndrome. Information may be heard, but in many cases the information gets jumbled like a telephone line when the wires are crossed, thus creating a party line. When that occurs, the result is mis-

communication and many questions. How many questions can a person ask before he or she becomes suspect? Some supervisors may perceive that an employee who asks too many questions is noncompliant (Muller, Schuler, Burton, & Yates, 2003).

Shore is an adult on the Autism Spectrum. He earned a bachelor's in Music Education and Accounting and Information Systems, and finished third in his class. An accounting firm hired him after he graduated from college. The environment at the firm was very conservative and straight-line. A suit and tie was the norm, and Shore did not like ties. He rode his bike to work and changed his clothes in the basement upon arriving at work. He shares his experiences with job duties and his interactions with supervisors and co-workers during his employment at the firm.

The assignment with a fellow accountant at the firm didn't work out well at all. I could never understand what he wanted and he seemed irritated at the things I did. The bank where we worked was overheated. In response to that, I would often open the window and take off my shoes when I was sitting at the desk out of view of other people. He didn't like that at all. While auditing a ledger, I mentioned to him that it was difficult to read some of the numbers.

One day the personnel manager called me into his office and told me he was letting me go. He said that I just didn't seem to fit in and suggested that there may have been a disability that I had failed to disclose to him when I interviewed for the job. That disability may very well have been there. To me, however, it was something of the past and it never occurred to me that accommodations may have been needed. I just thought that I was stupid because I didn't "get it." Getting fired was very humiliating and embarrassing to me. With a fuzzy, heavy feeling in my head, I gathered my belongings and left. (Shore, 2002, ¶s 6 and 7)

Shore's employment at the accounting firm lasted for three months, the usual probationary period. His boss felt that it was unacceptable behavior for Shore to change his clothes in the basement after he rode his bike to work. This job was one of many that Shore held over a three-year period. The firm was not a good fit for Shore and he sensed it. Did the interviewer observe any behaviors during the interview? Did Shore have a formal or informal interview? What characteristics did they observe in Shore? What kinds of questions were asked?

Shore possesses what some consider a lack of "water cooler humor." The water cooler in an office provides a temporary social outlet. Employees can gather at the water cooler during a break to have a drink, chat, gossip, and joke with one another. This is a time when people let their hair down and take time out from the hustle of the day. Shore was not interested in the topics discussed by his co-workers. When he went to the water cooler, it was only to get a drink of water. He held a few more jobs that were not good fits before he found the right place. Shore earned a doctorate degree in the field of Special Education.

Shore did not communicate his lack of understanding to his colleagues or supervisor. "Repeated miscommunications often lead to poor work evaluations and/or being fired from the job" (Muller et al., 2003, p. 168). Eventually, Shore's inability to communicate and seek out assistance in the work environment led to termination. Individuals with Asperger's Syndrome, like other people with disabilities, especially youth, lack the ability to problem solve in social situations and may not demonstrate appropriate self-determination, which often minimizes future positive social interactions with others (Myles, Barnhill, Hagiwara, Griswold, & Simpson, 2001). Being aware of one's strengths and weaknesses, as well as articulating one's needs in a realistic manner, is a first step to self-determination (Fullerton & Coyne, 1999). Letting others know that you did not understand what they said, and indicating likes and dislikes are important self-determination skills. In an academic setting, a teacher may be aware of a student's needs so guidance can be provided. However, in the work setting, disclosure becomes an issue. If a person is able to perform the essential duties of the job without accommodations, then he or she may not disclose a disability. For some reason, Shore did not feel the need to disclose to his employer. It appeared that the supervisor felt that he could not perform the essential duties of the job.

Studies by Ehlers and Gillberg (1993) estimate that 3 to 6 in 1,000 individuals have Asperger's Syndrome. However, The National Autistic Society (NAS) (2002) estimates that 1 in 100 individuals have Asperger's Syndrome. This disorder is more prevalent in males and usually runs in families (The National Autistic Society, 2002). Willey (2001) notes that she and her youngest daughter have Asperger's Syndrome. She also mentions that her father is self-diagnosed with Asperger's Syndrome.

Asperger's Syndrome was discovered in 1944, yet it was not recognized in the *Diagnostic and Statistical Manual for Mental Disorders* until 1994. Before 1994, many people

may have been diagnosed with other illnesses. Wing (2000) states, “Depression is particularly common and suicide rates are higher than would be expected for the general population” (p. 429). Tantam (2003) notes, “A range of medical disorders is reportedly more common in AS. These include epilepsy; disorders affecting brain development in childhood, such as hydrocephalus, tuberous sclerosis, and neurofibromatosis; congenital disorders of visual acuity and congenital causes of deafness; and disorders affecting motor control, such as myotonia and myopathy” (p. 147). Tantam also notes, “AS has a greater chance association with several other developmental disorders, such as Attention Deficit Hyperactive Disorder, Tourette syndrome, dysexecutive syndrome, developmental dyscalculia, and possibly some usual disorders of violation, such as elective mutism and elective dysgraphia, in which a person has an inability to write” (p. 148). However, the common denominator appears to be the inability to communicate and socialize with others. Imagine lacking something as important as communication and social skills. They also lack eye contact, which is important when communicating with others. These inability can hinder a person from actively participating in normal every day life activities.

Bower, a 31-year-old adult with High-Functioning Autism, is an information specialist. He admits that eye contact continues to be a problem. He states, “Either you get eye contact or you have a conversation with me. You can’t have both at the same time” (Hurlbutt & Chalmers, 2002, p. 105). Bower is willing to have a conversation, but on his terms. He is able to communicate with others on the job using a style that works for him.

People with Asperger’s Syndrome live with a secret that is not often discovered until they attempt to navigate through daily activities within the community, activities that many of us take for granted that lead to a fulfilling and productive life. I think about people with Asperger’s Syndrome and their constant desire to measure up to the social norms of society. Their inability to cope with social demands sets them apart from others in the community. How does a person measure up to a community that does not understand one’s complexities? It is disheartening to discover that a person who has earned a degree works as a dishwasher or a courtesy clerk.

### Measuring up in the Teaching Field

As I think about my experiences today with students who have Asperger’s, I think back to my earlier teaching experiences with special needs students... my challenges and theirs. From the start of my career, there were many questions. What can I do to help students with special

needs succeed? Where do I begin? What challenges are ahead? What should I expect? What will be expected of me as a teacher? Will I survive my first year?

I began teaching in the field of Special Education in 1986. I was so excited; I was going to change the world, or at least a small part of it. I was assigned to a self-contained class of students with Mild Mental Retardation in a junior high school not far from my home. It was a tough school, and attendance was a big issue. I had eight students: seven males, one female, and no assistant. The classroom was large enough for thirty students; instead, it was just the nine of us. My students were embarrassed to come into the room that the rest of the students in the school referred to as “the retarded class.” I share my earlier experiences to show my commitment to students and establish a context for the study.

### *Dated Books*

*Following the rules.* The Individuals with Disabilities Education Act (IDEA) Public Law 101-476, requires that every student identified as having a disability must have an annual Individual Education Plan (IEP) in order to receive services. The IEPs that I received for my students were past the annual review date, if they had an IEP at all. Therefore, I was expected to assess the students, write the IEP, and meet with parents immediately. Life was not good. This was a challenging group of students with whom to work. Many of the male students were physically in the school building, but did not attend class. When they did come to class, it took great effort to pull them into the lesson. The textbooks were ten or more years old and many of the books were missing pages, as well as covers. When I assigned homework, most of the students left their damaged books in the desks as they informed me “they were not taking those raggedy books out of this class.” Teachers in other content areas had brand new or newer books for their students. I thought, “What is wrong with this picture?” Are my students not worthy of having the same learning materials as the other students? Did the principal think that these students did not deserve or need newer resource materials? I was determined to obtain decent books for my students.

When I saw the principal in the hall, I asked him about getting newer books for my students since the books I received were missing pages and in poor condition. He looked at me and said, “I gave you what you needed for your students.” His eye began to twitch, and I sensed that my pushiness angered him. He said, “I’ll see what I can do,” and walked away.

The next day my supervisor appeared in my class. She told me that the principal called her about books. She went on to say that I should “make do” with the materials I was given. When I showed her the books, she had the strangest look on her face. The following day my supervisor gave me a small bag of high interest, low reading level books to use with the students. When I gave the books to the students, I could see that they met with their approval. My students only wanted what the other students had, decent books. The principal said very little to me after that day. I was surprised that an administrator would become so upset over books. After all, did the school not receive money for students with special needs? What was the problem? Did my supervisor express her disappointment about the damaged books to the principal? Why did he deny my students decent books? Did he not consider the students and me a part of the school? Was I considered an outsider using school space? By the way, what happened to my supply allowance?

*Hindsight.* As I look back at my teaching experiences, this first assignment speaks volumes. As I work with students who have disabilities, especially students with Asperger’s Syndrome, I constantly am confronted with changing attitudes about individuals with disabilities. Twenty-two years ago, books were barriers for students with disabilities receiving a free and appropriate education. Then, I fought for books!

Today, it still bothers me that these students are not given the same opportunities to have an appropriate education as their non-disabled peers. What image comes to mind when people think of disabilities? What makes people so apprehensive about the word disability? According to *Webster’s Third New International Dictionary of the English Language Unabridged* (2002), ability comes from Middle English word *ablete* and the Latin *habilitas*: aptitude. Ability is defined as (a) “the quality or state of being able: physical, mental, legal power to perform, and (b) natural talent or acquired proficiency, especially in a particular work or activity” (p. 3). *Merriam-Webster Online Dictionary* (2003) defines disability as (a) “inability to pursue an occupation because of physical or mental impairment,” (b) “lack of legal qualification to do something,” and (c) “a disqualification, restriction, or disadvantage.”

*Searching for meaning.* When I think about the word ability, independence comes to mind. By that, persons are able to work to support themselves, participate in leisure activities of their choice, and be a part of the community. I wonder if some people take the word ability to

mean flawless. We all possess skills to perform different tasks in our daily lives. Does that mean that we have to be flawless in our performance?

The word disability considers a person's physical and mental state as a reason for not pursuing a task. People with Asperger's Syndrome often are restricted from the employment process due to their inability to communicate effectively with others. This places them at a disadvantage each time they apply for a position. Muller et al. (2003) note that the application process, new routines, communication, and social skills are obstacles to successful employment for people with Asperger's Syndrome. For example, Mark has been out of school for almost a year. He has difficulty during the initial interview and has not realized his goal of employment yet. He is a willing and able body but is un-able to get his foot in the door to employment.

When a person has the ability to accomplish a goal and is halted by a dis-ability, he or she may feel dis-advantaged and dis-respected by those who hold opportunities in their hands. This population may be seen, but not heard. Their voices are minimized to a whisper among the crowd.

*A life sentence.* It is unfortunate that we live in a world of labels. Labels are meant to serve a purpose. In the field of education, labels are used to provide services to people in need of specific support. However, labels are not always used in the best interest of the person being identified. For example, when the label disability is used to portray injured military people, they are considered heroes or ones who made a sacrifice for the country. Nevertheless, they are still considered valued persons. On the other hand, when people are born with a disability or become disabled in life, they may be viewed as someone to pity. They may not be seen as complete persons. Where is the equity? Both groups have abilities and disabilities. Why do some people differentiate regarding disabilities? Are people with disabilities not entitled to the same opportunities as other people? Who is making these decisions? Is this discrimination at its best or worst?

I compare teaching students with disabilities to a salmon swimming upstream; I am fighting against a strong current, which keeps pushing me back. Am I winning or losing this battle? Now I am face to face with challenges of transitioning young adults with Asperger's Syndrome into the community. I wonder if the community will have a positive attitude. What opportunities will be available? What new battles are in store?

## *Cornered*

Imagine living in a corner tucked away out of the reach of others. People with Asperger's Syndrome live in the corners of life. They often are secluded from employment and social opportunities due to their unique demeanor. It seems that they often are swept like dust to a corner out of sight:

A corner that is "lived in" tends to reject and restrain, even to hide life. (Bachelard, 1964/1994, p. 136)

In some environments, a corner may represent success. One is considered successful when he or she has a corner office with a view. Yet, to be cornered can make one think of an unpleasant experience. Corner comes from the Latin word *cornu*, meaning horn. Corner is defined as "a threatening or embarrassing position from which escape is difficult; a remote, secluded, or secret place" (*American Heritage Dictionary of the English Language Online, 2003*). I recall a teaching experience that cornered me, and secluded me from the general population. I felt as if I were in a corner, and my corner had no view, only fumes.

I was assigned to an elementary school. When I entered the main office, I said "Good Morning," and told the secretary that I had an appointment with the principal. The principal came out to meet me, smiled, shook my hand, escorted me to his huge office, and offered me a seat. As quickly as his smile had appeared in the main office, it disappeared as he sat across from me and said, "I do not have a place for your class at this school." I began to shrink in my seat as I had heard this song before. The principal decided to give me a tour of the large old building, and as we moved through the halls, I noticed that teachers had staked their claim on each room. Nameplates were hung outside every room that we passed. Although the names were unfamiliar, I envied their claimed space. There was a space for everyone but me and my students. I was informed several more times during my visit that there was no room to accommodate another class.

We proceeded to the second level of the building, and stopped at a room located in the corner of the second floor. Actually, the room was at the top of the stairwell and was separated from the rest of the classrooms by large steel double doors. The space resembled a tower used to conceal secrets or institute punishment. Were we being punished? Bachelard, (1964/1994) notes that a corner ensures "immobility" (p. 137). Did the principal think that my students and I needed

to be contained? What made him choose this particular space? When the principal opened the door, the fumes of chemicals were suffocating. He walked into the room, opened the window and said, "This is the only space I have available." This bright yellow rectangular space served as the bookroom.

Part of the room was partitioned off into a closet, which the custodians used to store cleaning solutions. One wall of the room was lined with bookshelves from the ceiling to the floor. There were two windows and two large radiators that looked like they could produce more heat than anyone would ever need or enjoy. One wall in the room sweated to the point that the paint bubbled. I, too, began to sweat and my eyes began to itch. The principal smiled, thanked me for coming, and escorted me to the front of the building. What just happened here? What did I do wrong?

I closed my eyes and I found myself riding another roller coaster. I was always approaching the top. The slow motion and clinking sounds that the chains made as the car ascended to the peak of the ride let me know that there was no escape. The ride was long, bumpy, and terrifying. I was helpless as I sat tight to wait for the ride to come to a complete stop before I could be free again.

When I arrived at work, the secretary gave me the key to my classroom. Did she make a mistake? Was this a joke? The room that the principal showed me during my visit turned out to be my classroom. I have the before and after pictures to prove it! The fumes in the room were so intoxicating that the windows had to remain open at all times. It was unhealthy to breathe in the fumes all day. I spoke with the principal, the custodian, headquarters, and the parents about the fumes, but nothing was done. As the year wore on, the students and I were noticed less and less, and our voices became more silent. In this experience, I felt cornered, having no options, nowhere to go. I had to take what was given to me. By the end of the year, I was frustrated. Being isolated from my colleagues with little support was too much to bear.

Young adults with Asperger's Syndrome seem to be cornered by their disability and a community that does not understand them. I observe these adults in both the community and the workplace. They give it their best as they try to fit into the open space of the community and workplace. Yet, despite their best efforts, they often have difficulty finding their place. As a result, they usually are displaced, moving from scene to scene in hopes of finding a place. Will

others hear their voices? Will they be able to handle a corner? Will they gravitate to smiling faces in the crowd? Will they know whom to trust?

Samuel gravitated to faces that he considered friendly. He wanted to be a part of the group so much that he paid as if friendship was a service. Instead of being received with open arms, Samuel was met with outreached hands for a payment for the privilege of being in the company of the socialized others. Samuel lacked the skills to read beyond the smiles and the charge for friendship. He took his peers at face value.

### *Early Morning Visit*

One morning while I was meeting with parents, a student named Mark walked into my office. The door was closed, but Mark was undeterred. He opened the door and began, "Hey Ms. Miles, when can you get me a job?" The parents and I were startled. Mark did not acknowledge the parents or the fact that I was involved in a meeting. There was no, "Excuse me," or "I'm sorry for interrupting." He continued, "I want to know when you are going to find me a job?" I said, "Mark I am having a meeting and I will meet with you later." Mark responded, "When will you meet with me?" I said, "This afternoon." Then he said, "What time? What time are you going to meet with me?" I said, "I will pick you up during the last fifteen minutes of school." He stood in the door and continued to ask questions. The parents just stared at Mark and I quickly excused myself from the meeting and escorted Mark back to class. He continued asking questions about a job until we arrived at his class. Even then, Mark wanted to continue the conversation. Again, I told Mark that I was in a meeting, and would talk with him in the afternoon.

To the ordinary observer, Mark's behavior would be dismissed as rude, but Mark is functioning in a world that misreads such actions. What Mark displayed is actually typical behavior of people with Asperger's Syndrome, a disorder that impairs social functioning. Did Mark think it was okay to enter a closed door without permission? Did he even notice that I was not alone? What were his thoughts when he approached the closed door? What does a closed door mean to him?

When Mark entered my office without knocking or permission to enter, I was taken aback. He began talking without acknowledging the visitors in the room. I wondered if Mark even noticed the four people that were seated at the table in my office. After the meeting, I spoke

with Mark about entering an office without knocking. He looked at me and said, “Okay,” and continued to tell me what type of job he wanted. As I sat and listened to Mark, I thought about his transition into the world of work and into the community.

What effect would his behavior have on him obtaining and maintaining a job? What services would he need to survive in the community? I realized that I must learn more about Mark and other students with Asperger’s Syndrome. Was Mark’s behavior typical, or did it demonstrate his certain idiosyncrasies? If so, why are some of us so skilled in hiding them from the public eye or showing reserve behaviors? Van Manen & Levering (1996) define reserve as to hold back, to keep apart. The term reserve describes the tendency to conceal personal faults and shortcomings. What is it like to live in a body that cannot read the body language of others? Why is this held against people with Asperger’s Syndrome?

*Building trust.* Teaching people with Asperger’s Syndrome requires that you first build a relationship. Building a relationship helps to establish trust. Observation is another important component when working with this population. When working with students with Asperger’s Syndrome, it is so important to assist them to transition from one environment to the next. For example, when students are scheduled to participate in an activity, I have discovered that it is good to provide them with as much information about the activity and people involved as possible. This allows them to ask any questions and become familiar with the people involved in the activities in order to be comfortable when they arrive.

When Mark entered my office, his one thought was to get a job. He knew my name, title, and job duties. Mark wanted a job offer before leaving my office. This was my first encounter with him. His unannounced entrance into my office appeared rude and his many questions, annoying. However, as I began to work with Mark, I saw a young man who was determined, inquisitive, and eager to work. These things came through as I developed a relationship with Mark over the school year.

My experience with Mark made me wonder how I could provide students with Asperger’s Syndrome the guidance and right tools for surviving and thriving in adulthood. I wonder what level of collaboration will be necessary between the school, families, employers, and the community to increase the independence of students like Mark. There is often a lack of understanding and a fear of differences and disabilities, which often prevent young people with

Asperger's Syndrome from actively being involved in the community and maintaining stable employment. I wonder who will take the time to get to know these young adults with Asperger's Syndrome. I wonder how tolerant the employer will be towards these young adults. Will they see a diamond in the rough?

*Looking for the truth.* Earlier, I talked about my first teaching experience and the fight for decent books. What was the fight really about? Was it books that I fought for, or the right of students with disabilities to be treated fairly? Why were my students denied access to decent books? What does it mean to be different? Different comes from the Middle English word *differren* meaning to distinguish. It is defined by *Webster's Third New International Dictionary of the English Language Unabridged* (2002) as "partly or totally unlike in nature, form, or quality" (p. 630). *The Oxford Concise Dictionary of English Etymology* (1996) defines different as "put off" (p. 124). When I look at people around me, I am reminded how differences make us unique. What does it mean to be recognized by difference?

There is a strong tendency in all human individuals and groups to maintain this egocentric attitude and to think of individuals either as extensions of the self, or as alien objects to be manipulated for the advantage of the individual or social self. (Levinas, 1961/1969, p. 12)

This says a great deal about people and their approach to selecting others with whom they associate. As Levinas notes, people are viewed as either similar or different based on a person's perception. What do we have in common? We experience this in our daily life activities. We have a tendency to relate to people who share a similar educational background, occupation, hobby, lifestyle, or social affiliation. People with Asperger's often are perceived as different and others may not find any commonalities with them. They stand out in social settings like a square in a circle; they do not fit perfectly. This imperfect fit may open the gate for people with Asperger's to be taken advantage of by those who observe such differences. We all have differences that are both visible and invisible. Why is difference embraced when expense or status is attached? If a person owns a 5-carat ring or is a member of a wealthy family, they are considered different. Is it possible that difference is accepted when it is observed in objects rather than people?

I am still fighting battles as I continue to prepare students with Asperger's Syndrome for adulthood, but these new battles are no longer about books. In fact, I have more new books than I can use. Over the years, I have learned that the confrontation with the principal was not just over books. The confrontation was really about the rights of students who are different, and I suspect that I will continue to struggle to change people's attitudes about students who are different. I am like the salmon that continues to swim upstream.

*Swimming against the current.* What does this struggle mean? According to the *American Heritage Dictionary of the English Language Online* (2003), struggle comes from the Middle English word *struglen*. Struggle means (a) "to make a strenuous effort; strive, (b) to contend or compete, and (c) to progress with difficulty." At times, we all struggle as we strive toward our goals. *The Oxford Concise Dictionary of English Etymology* (1996) defines struggle as "contend with close grapple" (p. 467). We often are able to pull through the struggle, or if it gets too complex, we may decide to make another choice. Many people may seek support to help them reach their goal. However, people with Asperger's Syndrome constantly struggle in their daily activities. Those struggles are compounded by their inability to read a situation or advocate for themselves when a problem arises.

I observe the struggles of these young adults as they search for their place in the community. Mark struggles with developing friendships, while Karen struggles with communicating with others. These struggles may seem minor to many of us. Yet, they can be overpowering for people with Asperger's, especially when support systems are not available during those times of need.

As I work with students with Asperger's Syndrome, I feel that I have a responsibility to help them develop independent living skills that will serve them well in the community and in the workforce. The book experience taught me to pick my battles wisely. What will young adults with Asperger's Syndrome do when they happen upon people like my former principal in the community or in the workforce? Will they be able to handle the words, "I'll see what I can do?" Will they know what the silence really means? Will they know how to pick their battles? The silence of body language can be compared to reading a book; the interpretation rests on the reader's perception. Communication is paramount in any encounter that we have with others in our daily lives. Yet, the body can communicate a lot without using a single word. For example,

silence in communication can show that one person is listening to the speaker. Silence also can be a secret way of shunning a person.

*Silence is golden.* According to Webster's Third New International Dictionary of the English Language Unabridged (2002), silence comes from the Latin word *silentium*. Silence is defined as (a) "forbearance from speech or noise, and (b) absence of mention" (p. 2116). I have felt such silence in my past teaching experiences. Mark felt the silence first when he entered my office. Then he felt it again with classmates. Karen feels the silence when she is caught in an emotional traffic jam. Nonetheless, in order for me to assist students with Asperger's Syndrome with their transition struggles, I return to my own struggles from the past and think about what they might reveal.

Interacting with others within the community is important to our survival, and it does not matter whether the interaction is on a social or professional level. People with Asperger's Syndrome lack the soft skills that employers require for all workers. Individuals in the community, especially a work setting, have the opportunity to provide honest feedback, one event at a time, regarding acceptable and unacceptable behaviors. Continued feedback, practice, and monitoring behaviors by a circle of friends and peer supports within the work environment and the community could prove beneficial. Much practice is required to assist people with Asperger's Syndrome to become a part of their community without fear of rejection.

Natural support systems often exist in the form of a sympathetic friend or neighbor who is willing to comfort others during times of need. Support systems can assist individuals with Asperger's Syndrome by providing feedback so that the individual can feel comfortable in everyday situations or public settings (Myles et al., 2001). A co-worker could serve as peer support in the work environment by modeling social behavior and helping the employee to better comprehend nonverbal communication.

I think about Shore's experience at the accounting firm. Would he have had a better chance of being successful on the job if he had a support person to assist him to make a smoother transition? Surely, a support person could have pulled him to the side to inform him that it was unprofessional to remove his shoes or been a listening ear when he did not understand an assignment. Shore may not have appeared to be so far removed from his supervisor and co-workers. Muller et al., (2003) note, "Negative experiences are frequently attributed to poor job

matches, inadequate time to learn new tasks, lack of tolerance for differences within the workplace, and problems interacting with supervisors and co-workers” (p. 166).

### Marching to the Beat of a Different Drummer

The beat that people with Asperger’s Syndrome choose to march to in life may seem out-of-step with those around them. They may appear eccentric in social situations, demonstrating behavior that raises a few eyebrows without an offer of apology. Are they that different from you and me?

Bock (2001) shares her dining experience with Carol, an adult with Asperger’s Syndrome. While Bock was dining with a friend, Carol walked into the restaurant past the *maitre’d* to their table. She did not have a reservation, nor did Bock invite her to join them. She ignored the *maitre’d’s* summon and sat down at the table. Bock informed the *maitre’d* that Carol could join them. Carol did not greet Bock and her dining guest nor did she acknowledge the waiter. She began questioning Bock about her thinking process, and then went on to explain how she thinks. Instead of placing her order with the waiter, Carol walked into the kitchen and placed her order. A chef delivered her dinner; she ate quietly, paid the *maitre’d* and walked out of the restaurant. To some, this may seem to be rude behavior. Yet, Carol noticed a familiar face and saw no harm in joining them for dinner.

### *Out of Beat*

If a man does not keep pace with his companions, perhaps it is because he hears a different drummer. Let him step to the music which he hears, however measured or far away. (Thoreau, 1854/1995, p. 210)

This quote by Thoreau speaks well for people with Asperger’s Syndrome. They march to a different drummer. They navigate through life to the tune of their own unique beat, despite the fact that others may find their ways odd. People with Asperger’s Syndrome often are misunderstood. They may be seen as strange due to their inability to conform to the social rules set by society, yet they can lead active and productive lives in the community. Everyone who marches to the beat of a different drummer may not have Asperger’s Syndrome. They may choose to be different. However, for people with Asperger’s Syndrome it is not a choice to be different, it is the one way he or she knows how to navigate in the world.

What does it mean to march to the beat of a different drummer? Why does that make some people feel uncomfortable? My parents used to say, “Be yourself,” and “Stand on your own two feet.” I interpreted those words to mean be unique and not a carbon copy of anyone else. Yet, it appears that when a person does not fit in or marches to a particular beat within the community, he or she may be considered odd. People with Asperger’s Syndrome rationalize differently than people in mainstream society and, therefore, their rationale for doing things may be misunderstood by some in the community (Willey, 2001). Howlin (2000) describes individuals with Asperger’s Syndrome this way: “There may be constant pressure to ‘fit in’ with the demands of a society that fails to understand their needs or difficulties” (p. 79).

Perlman (2000) notes, although these adults want to interact with others, they are unable to relate. Visualize the adult who interrupts and takes control of conversations by inundating anyone nearby with excessive details about a topic. The individual with Asperger’s Syndrome may pay little attention to whether or not others are interested in the subject because in this adult’s mind, he or she is just being sociable. Individuals on the receiving end of the conversation may view this behavior as being rude, insensitive, and self-centered (Barnhill, Cook, Tebbenkamp, & Myles, 2002). According to Attwood (1998), individuals with Asperger’s Syndrome lack “social common sense” (p. 33). Frith (1991) notes that individuals with Asperger’s Syndrome lack theory of mind. She states, “They can tell what a scene looks like for different people at different places, but they cannot understand somebody else’s point of view if by this we mean somebody else’s attitude or belief” (p. 19). I return to Mark’s experience with the yearbook. Did Mark expect the students to assume that he wanted to view the book?

Individuals with Asperger’s Syndrome also have boundary issues. Thus, an individual may stand too close in proximity to another person, failing to read the body language (Safran, 2001). For example, an individual with Asperger’s may stand too close to a person when asking a question or waiting in a line, without realizing such closeness may be considered an invasion of personal space. The person with Asperger’s may not be able to read the facial expression of a person who may be uncomfortable with such closeness of a stranger in their personal space. How do you respond to such closeness in a crowd? What is your response signal to the person with Asperger’s Syndrome?

Willey (2001), an adult with Asperger's Syndrome, noticed spinach stuck between the teacher's teeth. She moved toward the teacher so that she could remove the spinach from between the teeth of her daughter's teacher. As Willey moved toward the teacher, the teacher stepped back. Willey's daughter jumped from her seat and grabbed her mother's arm to halt her action. Did Willey think that the teacher would have allowed her to pick the spinach out of her teeth? What other experiences occurred at school in the past to cause Willey's daughter to jump from her seat to stop her mother? This often leads to impolite comments from another person. Willey may not have thought it was unacceptable behavior to remove the spinach from the teacher's teeth. Besides, she has known this teacher for a whole year. Was Willey's objective to save the teacher embarrassment? Did the spinach between the teacher's teeth annoy Willey?

When I read the educational background of students with Asperger's Syndrome, I always am amazed at their academic potential. A person's inability to communicate, poor grooming, and peculiar behaviors frequently becomes a barrier to successful socialization in a variety of settings. Although these individuals usually have average to above average cognitive abilities, they often demonstrate behaviors that most people in mainstream society consider bizarre or offensive (Willey, 2001).

Mark has been out of school for one year, and is still having difficulty finding a job. He is interested in finding an entry-level position in the transportation field, desperately wanting to work for Washington Metropolitan Transportation Agency. Mark completes application after application for entry-level positions. So far, he has not been granted an interview. After he submits an application, Mark calls the agency more times than necessary. Once, Mark requested to speak to the head of the company regarding the status of his application. He did not understand how the chain of command works in the business community. Therefore, calling an agency and insisting to speak to the head person did not appear to be out of the ordinary. Of course, his calls were not returned, nor was he granted an interview. Mark keeps asking "Why?" and "When?" Why did the president of the company not call him back? When will the company call him for an interview? Mark wants a job. He feels that it is unfair when companies do not call him back. Despite the silence of his telephone, Mark continues to check on the status of his applications. How long does Mark have to ask "why?" before he realizes his dream of employment? Hurlbutt and Chalmers (2002) say, "Underemployment and unemployment are real

problems for people with autism” (p. 108). They interviewed Eugene, an adult with autism. He says, “Our society values surface over substance. This hurts people with autism” (p. 108). They do not share the same experience of having the advantage of a level playing field in the job market. What will it take to end this cycle? When will they be seen for their contributions rather than their idiosyncrasies?

### *Cracking the Communication Code*

Gray (1998) compares nonverbal communication to a “secret code.” A raised brow, a look of surprise or excusing oneself from the conversation may signal disapproval of a particular comment made during a conversation. The “code” provides important information for most people; however, for an individual with Asperger’s Syndrome, it has little or no meaning. Initiating a conversation or even telling and responding to jokes can be difficult for people with Asperger’s Syndrome. According to the National Autistic Society (2002), individuals with Asperger’s Syndrome have difficulty understanding jokes because they take the meaning literally. Idioms like “It’s raining cats and dogs,” or “The early bird catches the worm” are too abstract and can lead to confusion and many questions. Play on words becomes hard work and makes little sense to a person with Asperger’s Syndrome.

While engaged in a conversation, some individuals are able to read body language or a facial grimace and respond accordingly. People with Asperger’s Syndrome are limited in their ability to read body language, as Mark did when he barged into my office. Our startled facial expressions had little meaning to Mark. He had a purpose for being at my office door, was persistent in getting his questions answered, regardless of what else was going on around him at that time.

Distinguishing residual or unwritten rules set by society appears to come easily to some people, but is often difficult for people with Asperger’s Syndrome to understand. In a social setting, one does not invite him or herself to a social gathering. Yet, Carol invited herself to dine with Bock. She was hungry, saw a restaurant of interest, spotted a familiar face, and joined Bock and her friend for dinner. In a work setting, something as small as knowing which chair the supervisor uses during a meeting and leaving that chair vacant for the supervisor is an unwritten rule that usually is acknowledged on the job.

Mark confronted his supervisor about his assigned duties. He complained that his supervisor wanted things perfect. He went on to say, “He wanted his cake and eat it too.” Mark questioned his supervisor’s procedure each time he was given an assignment. After a few days of this kind of questioning, the supervisor asked Mark to choose his last day. He did not follow the rules of the workplace. Was this the only reason why Mark lost his job? I wonder if Mark’s supervisor held an exit interview with him before terminating him, or did he just show him the door?

People with Asperger’s Syndrome are oblivious to things out of sight. Inflexibility is often a reason why an individual with Asperger’s Syndrome will lose his or her job. Hurlbutt and Chalmers (2004) suggest that adults with Asperger’s Syndrome have not been successful at obtaining and maintaining employment due to their inability to relate to others on the job. Today, the workplace expects employees to have the ability to multi-task. The in box is never empty, and there is often a new task to perform and problems to solve. Many people just perform work tasks without giving them much thought. Situations on a job can change in an instant as priorities change. When these situations occur, it is expected that everyone exercise flexibility.

The work environment offers a person the chance to demonstrate his or her skills in a chosen career field. This environment is often a place where teaming and friendships develop among co-workers. Employees also strive toward promotions, and most people want to be in a job that offers that potential. A promotion represents success on the job. Yet, some people with Asperger’s may not accept upward mobility positions if social interaction is required (Wing, 2000). Xenia, a 35-year-old woman with Asperger’s, has a degree in political science, but works as a data-entry clerk. She likes the position but wants to find a satisfying and meaningful job (Hurlbutt & Chalmers, 2002). Why did Xenia not seek a position in the field of political science? What does Xenia consider satisfying and meaningful employment? It appears that Xenia is willing to work, but has not found the right job. I wonder if Xenia is like others with Asperger’s who choose positions that allow them to work alone in silence over a position that requires social interaction with others.

*Shush!*

Silence is usually something that we choose to experience. Sometimes, when a person is too loud in a public place, you may hear someone say shush. At other times, silence may be

welcomed, especially during stressful times in our lives when we need to collect our thoughts or to break from the hustle of our busy routines. Silence can be a big part of the life of persons with Asperger's. However, their silence is not the usual need for quietness and being left alone. Their silence comes in the form of avoidance. For example, a party atmosphere will have an expected level of noise. Noise usually represents an atmosphere of having a good time. This atmosphere allows for an acceptable amount of interruption during conversations to get a point across. In addition, unacceptable conduct by a few people is often tolerated during the festivities. Yet, some people may perceive a person with Asperger's as condescending especially when they control a conversation. Often, the person politely excuses himself to search out others who will allow them to voice their point in the conversation. At that point, it can become a shush moment for the person with Asperger's Syndrome.

Historically, adults with Asperger's Syndrome were diagnosed with schizophrenia during childhood. The diagnosis of schizophrenia may have explained the reason for odd behaviors in the past and present. Imagine that for 15 years you believed that you were a person with schizophrenia, only to learn later in life that you have been misdiagnosed and what you have is Asperger's Syndrome. What does this new diagnosis mean? Where does one go from here? Once again, the silence takes over.

### *Forgive and Forget*

Despite the support of family and friends, some adults with Asperger's Syndrome are unable to develop and maintain personal relationships independently. If you ask persons with Asperger's Syndrome to name at least three friends, you may discover the difficulty they may have to produce names. People with Asperger's Syndrome want to experience the same intimate and platonic relationships as others. Is having a relationship too much to ask? Why is this so difficult for this group of people? What can they do to have the same relationships as everyone else? It is so disheartening to observe these individuals reach out to others the best way they know how only to be rejected because of their mannerisms. We all have experienced situations where someone demonstrated unacceptable behavior. What action was taken? Often, people forgive and forget. The behavior was accepted and was not used against that person. Behaviors are blamed on a bad day, stress, the wine, or other factors. Imagine demonstrating unacceptable behavior on a daily basis, without anyone understanding the cause, forgiving, or providing the

excuse of too much wine. This is what people with Asperger's Syndrome may experience in their day-to-day activities.

Adults usually enjoy a quality of life that includes family, friends, work, and leisure activities within the community. Yet, adults with Asperger's Syndrome often have difficulty developing and maintaining both intimate and platonic relationships in the community.

The rule of behavior that seems to be common to all situations and exclusive to them is the rule obliging participants to "fit in". The words one applies to a child on his first trip to a restaurant presumably hold for everyone all the time: the individual must be "good" and not cause a scene or a disturbance; he must not attract undue attention to himself, either by thrusting himself on the assembled company or by attempting to withdraw too much from their presence. (Goffman, 1963, p. 11)

Goffman's quote refers to a person fitting in. He goes on to discuss that a person should not call attention to himself or withdraw from others while in the public eye. Yet, for a person with Asperger's, behavior often hinders the chance of fitting into the group. Comments or requests made to others may be construed as simply unusual. The following experience is an example of calling attention to oneself while in the public eye.

As Charlie rode the elevator to his interview, a stranger said pleasantly, 'Nice day, isn't it?' Just then Charlie happened to see his reflection in a mirror by the elevator buttons. His hair was sticking up in a peculiar way and had no comb with him. He turned to the friendly stranger and asked, Do you have a comb I could borrow for a minute, please? (Attwood, 1998, p. 41)

I wonder why Charlie asked a stranger for a comb. Has he done this before? Did the stranger comply with his request? The way people communicate often can determine whether they are accepted or rejected by others. When two people meet, both parties do a certain amount of assessment based on the other's ability to interact in a socially acceptable manner. If a person demonstrates behavior that is considered unacceptable, it is unlikely that a second interaction between the parties will occur. As a result, others may avoid these adults in a work or social setting rather than tell the individual that his or her actions are unacceptable. What are the rules

of the social game? Who decides when, where, and how those rules will apply? Will someone explain the rules?

*Reading Between the Lines of Employment Etiquette*

While engaging in work activities, an individual with Asperger's Syndrome often takes on the role as the enforcer of the rules. For example, an individual with Asperger's Syndrome will make sure that a peer follows the rules as written, and will insist on fair treatment among the entire group (Attwood, 1998). In a work environment, this can cause conflicts with co-workers and supervisors. A supervisor may misread the actions as insubordination, instead of a lack of understanding on the part of the employee with Asperger's. When Mark questioned his supervisor's directives, it may have been interpreted as insubordination.

Because individuals with Asperger's Syndrome also have boundary issues, a co-worker who feels uncomfortable could open the door to a harassment grievance where there truly is not one.

By the time he was in college, Joe was interested in meeting young women and dating but was unsuccessful in his attempts to start a relationship. He often called women on the phone too much and drove them away by not recognizing their feelings of being harassed. (Hurlbutt and Chalmers, 2004, p. 217)

Did Joe believe that his persistence would make the woman change her mind? Often these character traits are barriers for adults with Asperger's Syndrome and often affect their ability to develop and maintain friendships and working relationships with others.

Individuals with Asperger's Syndrome often lack the flexibility to move out of their comfort zone without some prompting (Safran, 2001). For example, an employee may be used to taking his or her break at 9:30 a.m. under one supervisor. When a new supervisor takes over and changes the break to 10:00 a.m., the employee becomes highly agitated. Changes in the routine can create frustration and sometimes anxiety (Powers & Poland, 2002). The individual with Asperger's Syndrome often has a difficult time adjusting to the new change.

A person's inflexibility or inability to interact socially with others can be a barrier to developing and maintaining successful friendships and employment. An individual with Asperger's Syndrome lacks self-awareness (Barnhill, 2001; Safran, 2001) and does not realize

the damage caused by such comments. The repercussions of these behaviors often result in avoidance. I wonder if Shore was offered any assistance before he was terminated from his job.

The experience shared by people with Asperger's demonstrates how they keep in step with the demands of life's daily activities. They do not offer an apology for their actions. However, they do desire to be a part of the social world and some put forth a great effort to fit into the social and work circles. Yet, their be-ing with others often creates frustration for both sides. The result is a collision of the two worlds, the "Aspies" and the "Neurotypicals." Do we have to like the same beat in order to live in the space? I wonder what compromise can be made to create harmony and understanding within the two worlds.

### *A State of Being*

It is clear that the life-world is always at the same time a communal world that involves being with other people as well. It is a world of persons and in the natural attitude, the validity of this personal world is always assumed. (Gadamer, 1975/2003, p. 246)

Socialization begins during childhood. Parents, schools, and community prepare children to socialize with others through organized learning and recreational activities. Socialization allows individuals to get to know and learn from one another. People with Asperger's Syndrome socialize the best way they know, in a way that is normal in their perception. According to Frith (1989), this group lacks the pretense. For example, a game of hide and seek may present a problem for a person with Asperger's Syndrome. This group may not understand the rules of the game. While others run to find that perfect hiding place, a person with Asperger's Syndrome is still figuring out what to do, thus missing the fun. Most often, people with Asperger's Syndrome usually end up on the outside looking in. They become mere spectators. Is it that difficult to create an inclusive social environment for all? Communication can help others gain a better understanding of those with Asperger's Syndrome.

### *Finding a Place to Call Home*

Our lives are so place-oriented and place-saturated that we cannot begin to comprehend, much less face up to, what sheer placelessness would be like. For this reason, we rarely pause to consider what being no place or having no place might mean. Even when we are displaced, we continue to count upon some reliable place, if not our present precarious

perch then a place-to-come or a place-that-was. While we easily imagine or project an ideal (or merely a better) place-to-be and remember a number of good places we have been, we find that the very idea, even the bare image, of no-place-at-all occasions the deepest anxiety. (Casey, 1993, p. ix)

What does it mean to be "at home"? What does this place called home represent to an individual? Why is it so important for one to be or feel "at home"? Does a home have to be a structure, or is it just a state of mind? Does a home need four walls in order to be considered a home? Is home just a shelter from the elements? Is it just a safety net in times of danger? What does it mean to find your place? Casey (1993) also writes, "Being guarantees place" (p. x). If this is so, why do some people feel so out-of-place? Why do some people have difficulty finding a place to call home? Why are some still in search of a home to call their own? I wonder what it is like for a person to feel deprived of "feeling at home" in a society that endorses membership. What about the words, "There's no place like home." Do these words apply to all citizens or a select few? What does it mean for people of different lifestyles? As I reflect on the lives of people with Asperger's Syndrome, I think about what home means to me, and what it might mean to people with Asperger's Syndrome.

#### Turning to the Phenomenon to Open up Place

Phenomenological human science is the study of lived or existential meanings; it attempts to describe and interpret these meanings to a certain degree of depth and richness. (van Manen, 2003, p. 11)

When I began working with students with Asperger's Syndrome, I was astounded by the way they experienced the world. No two students presented the same way. I want to gain a better understanding of these students and want others to do the same. I am oriented to the phenomenon of Asperger's Syndrome as an educator and citizen. As I journey into the world of Asperger's Syndrome, I feel that it is necessary to bring forth the richness of the experiences. The best way to do this is through their voices and in their own words.

I return to the question: **What is the lived experience of persons with Asperger Syndrome?** As I reflected on the experiences of people with Asperger's, I sought to use a research approach that would show this disorder and give voice to people with Asperger's

Syndrome. I used phenomenology as the foundation for the journey into the lived experiences of people with Asperger's Syndrome. As further discussed in Chapter 3, the methodological structure used as a framework for the study is developed by van Manen (2003), in *Researching Lived Experience*. The structure is divided into the following six research activities:

- 1) turning to a phenomenon which seriously interests us and commits us to the world;
- 2) investigating experience as we live it rather than as we conceptualize it;
- 3) reflecting on the essential themes which characterize the phenomenon;
- 4) describing the phenomenon through the art of writing and rewriting;
- 5) maintaining a strong and oriented pedagogical relation to the phenomenon; and
- 6) balancing the research context by considering parts and whole. (pp. 30-31)

“Phenomenology is keenly interested in the significant world of the human being” (van Manen, 2003, p. 9). I am interested in people with Asperger's experiences. I desire to understand them as people who live with us in the community. Earlier, I shared some of their experiences as they live them. I continue to observe challenges that students with Aspergers have in school. These challenges follow them into adulthood. School is a place where students usually develop friendships and memories of good times. Students with Aspergers do not always share the good times that their non-disabled peers celebrate.

Van Manen (2003) states, “Phenomenology aims at gaining a deeper understanding of the nature or meaning of our everyday experiences” (p. 9). Earlier, I examined my teaching experiences to gain a deeper meaning as an educator of students with special needs. I seek to gain a deeper understanding of the experiences of people with Asperger's Syndrome. It is my hope that this study will move others to take a closer look at the person, instead of making assumption about the behavior. Although they may not possess the people skills that employers expect, they have the skills to perform the essential duties of the job.

### *Assumptions*

As I journey through the world of people with Asperger's Syndrome, I am aware that what I know about the disorder can have an effect on the study. According to van Manen (2003), “The problem with phenomenological inquiry is not always that we know too little about the phenomenon we wish to investigate, but that we know too much” (p. 46). It can be a difficult task to step outside of what we know, especially when you feel so passionate about it. How does

one play the role of not seeing, hearing, or knowing about the phenomenon? I believe that as a researcher I must keep in mind the purpose of my study at all times.

For the interpreter to let himself be guided by the things themselves is obviously not a matter of a single “conscientious” decision, but it is “the first, last, and constant task.” For it is necessary to keep one’s gaze fixed on the thing throughout all the constant distractions that originate in the interpreter himself. (Gadamer, 1975/2003, p. 267)

Distraction may occur during the process. However, in order to accomplish this task, I used a wide-angle lens as I explore the literature and work with people who have Asperger’s Syndrome. I cannot erase what I know about Asperger’s Syndrome and the experiences of those with this disorder. Nonetheless, I can review experiences and literature with fresh eyes to bring forth the essence of the phenomenon.

Cash (1999) notes that people with Asperger’s Syndrome live in two different worlds, one of strengths and the other of weaknesses. In these worlds, the strengths are acknowledged and the weaknesses are often misunderstood. Balancing daily interactions in the two worlds can be a struggle.

Adults with Asperger’s Syndrome have the capabilities to participate in postsecondary education opportunities. Some may even earn multiple degrees during their lifespan. Many have made great contributions to society. They work, play, vote, pay taxes, and have hopes and dreams as other citizens. They also live with a stigma, the label “peculiar.” This label often overshadows their talents and chance to develop and maintain relationships with others.

While Hans Asperger’s work occurred in 1944, Wing’s research during the 1980s renewed awareness regarding the syndrome. However, Asperger’s Syndrome was not officially recognized in the United States until 1994. Over the years, people with Asperger’s Syndrome have been misdiagnosed. Perlman (2000) has written that some people were diagnosed with schizophrenia during their youth. Wing (1991) has written, “Alternative labels mentioned are ‘schizoid disorder of childhood’ and autistic psychopathy” (p. 105). Once they reached adulthood, it was determined that they had Asperger’s. Many families with whom I have conversed share this same experience about their adult child. What does a person do with this new diagnosis? What exactly does it mean?

This study will describe the experiences of people with Asperger's Syndrome as they attempt to navigate in social and work environments. A person's inability to interact socially with others on the job often becomes a barrier to future employment opportunities. Many adults with Asperger's Syndrome often are fired after a short period on the job simply because they lack the social skills needed to adjust in the work environment. Even though these individuals possess the knowledge and skills in a particular career field, they usually hold positions that do not match their skills (Hurlbutt & Chalmers, 2002). Awareness, ongoing support, and resources are important ingredients for successful employment of adults with Asperger's Syndrome.

It is my hope that this investigation gives a voice, a face, and a place to people with Asperger's Syndrome. Casey (1993) speaks of place-separation (feeling out of place) "not feeling at home" (p. x). Everyone is entitled to find a place that he or she fits into comfortably. This place allows persons to express themselves without any reservations.

Mark, a former student who entered my office early one morning, started me on this journey. His style of navigating the world around him often prompted others to stare or even make jokes about him. The forming of my commitment to "Special Need" students was born out of my experiences as a Special Educator attempting to support students with disabilities transition to work from school. The swim was a long and sometimes tiring effort; nonetheless, the shoreline (rights to a free and appropriate education) continues to be my main goal.

As an educator, I want to serve as a guide to students with Asperger's Syndrome to increase their awareness of boundaries and enhance soft skills necessary to survive within the community. People with Asperger's Syndrome learn, think, and respond in a manner that makes sense to them. Their way of navigating communication or social skills in their daily life activities may appear bizarre to some. Should we work so diligently at changing or fixing them or helping them integrate into the community? What does this mean for people with Asperger's Syndrome who have contributed to society? Does being different make a person less of a citizen?

Merleau-Ponty (1945/2003) writes, "[Phenomenology] tries to give a direct description of our experience as it is, without taking account of its psychological origin and the causal explanations which the scientist, the historian or the sociologist may be able to provide" (p. vii). Phenomenology gives me the freedom to reflect on and reveal the rich experiences of people with Asperger's Syndrome in a lived manner, rather than a conceptual or theoretical one.

Phenomenology also gives me permission to use a variety of sources to investigate the phenomenon. Art, etymological sources, poetry, biographies, diaries, journals, and other sources add to the richness of the study. Phenomenology permits me to start with my own experience in my journey to describe and interpret the meaning of the phenomenon. “The aim is to construct an animating, evocative description (text) of human actions, behaviors, intentions, and experiences as we meet them in the lifeworld” (van Manen, 2003, p. 19). In this study I observed, and had conversations with people having Asperger Syndrome to bring this phenomenon to a better understanding for people in every day life.

It is the process of humanizing human life and humanizing human institutions to help human beings to become increasingly thoughtful and thus better prepared to act tactfully in situations. (van Manen, 2003, p. 21)

People with Asperger’s are often viewed as peculiar due to their inability to demonstrate tact in various situations. Attention is usually focused on the behavior and not the person. I hope that after reading about and reflecting on the experiences of people with Asperger’s, all who interact with them will exercise patience and thoughtfulness rather than avoiding their presence. When they are face-to-face with a person with Asperger’s, they will see the person first.

### Continuing the Journey

In Chapter One I explored the background and shared experiences of people with Asperger’s Syndrome as they attempt to navigate through social and work settings. I also shared my earlier teaching experiences of working with students with special needs and the commitment that led me to the phenomenon of Asperger’s Syndrome. In Chapter Two, I investigate the lived experiences of people with Asperger’s Syndrome through various sources in the literature. In Chapter Three, I discuss the philosophical grounding, the methodological framework, the philosophers that connect to the study and questions guiding the inquiry. In Chapter Four, I uncover the themes found in the lived experience accounts of person with Asperger’s Syndrome and interpret the meaning that lies therein for themes to make sense of what the text is communicating. In Chapter Five, I discuss the pedagogical insights and recommendations for further research that may enhance the lives of people living with Asperger’s Syndrome.

## CHAPTER TWO:

### EXPLORING THE PHENOMENON: MEANDERING THROUGH THE SOCIAL MAZE

In Chapter One, I shared the experiences of people with Asperger's Syndrome as I brought forward the phenomenon and questions that call me to this study. I also shared my earlier teaching experiences that were significant in my commitment to persons with special needs such as Asperger's Syndrome. It is my desire that this study will provide schools and communities with useful knowledge about the lives of people who have Asperger's Syndrome, sharing their experiences as they live them and providing an understanding of their abilities and needs. Marks et al., (2000) have noted, "School personnel are often at a loss when developing interventions to address these areas of concern" (p. 4). Their experiences may afford insights into the specific support needed as they transition from school to adulthood. This study can contribute to the field of education for those students entering teaching and for current teachers. It can assist co-workers and employers to see ability first and maximize the potential of people with Asperger's in the workplace. Now I will take you on a journey into the lives of individuals with Asperger's Syndrome to open up a deeper understanding of this phenomenon. At times, the journey will be rocky, but it is my hope that you will hear the voices of people with Asperger's Syndrome as they struggle to find their place within the community.

In today's society, there appears to be a great need to belong. We establish kinships with others in school, our community, or on the job. We fit into a group of people we feel are like us and share the same values. Such groups can serve as social and professional networks, which can last a lifetime. We proudly pledge our allegiance and wear the colors that signify our association, smiling as others acknowledge our affiliation. We are the "chosen ones" and it feels good. What does that really mean? What makes us so special?

The longing to belong seems to be ancient and is at the core of our nature. Though you may often feel isolated, it is the nature of your soul to belong. The soul can never be separate, its eternal dream is intimacy and belonging. When we are rejected or excluded, we become deeply wounded. To be forced out, to be pushed to the margin, hurts us.  
(O'Donohue, 1999, p. 4)

I think about people who long to be a part of a group. Yet, for whatever reason, they

find themselves on the outside looking in. What does it mean to belong? What price is a person willing to pay in order to belong? What does it mean when you are accepted into the fold? The following experiences speak to those who attempted to fit in but were unsuccessful.

### Living in Different Worlds

The teenage culture in his school is hard for him to figure out, said his mother. And his in-your-face manner is causing him difficulty. He knows he must curb the anger he feels in confrontations with his teacher, so he's starting to hurt himself instead. Phillip (mother) has seen that self-abusive pattern in the past and it distresses her. A few years ago, miserable because his classmates excluded and bullied him, Daniel began head-banging and scratching himself. (Ruttan, 2004, p. A1)

Like other 16-year olds, the gangly [Ashton Smith] teen loved video games, developed crushes on pretty classmates and dreamed of the day he would drive. He desperately wanted to be like everyone else, but because of his autism he was instead often ridiculed and ignored. Like many teens with Asperger syndrome, a high-functioning form of autism, [Ashton] Smith was emotional... One day he could be giddy and excited about a sunset, then the next day become furious at his classmates and relatives for not understanding him. In the days after Smith finished his sophomore year at Mountlake Terrace High School, his mother, Roseanne Smith, said he had been happier than she could remember in a long time. So when he didn't come home on June 9, Roseanne Smith enlisted her friends and relatives to scour King and Snohomish counties in search of the dark-haired teen. She appeared on television and in newspaper reports. Strangers helped post her son's photo at bus stops and handed out fliers at Seattle Mariners games. (Sullivan, 2003, p. B1)

The anecdotes above represent a snapshot of experiences people with Asperger's Syndrome encounter in an attempt to belong. They try, but do not make the cut into the world of be-longing. They tend to find themselves a-lone, even in a crowd. Although they live in the same community, attend the same school, or work beside other citizens, they were unable to fit into the group. Daniel and Ashton were bullied and ignored by classmates. Daniel was so frustrated from his negative experience with classmates that he began to mutilate himself. Ashton, the sixteen

year-old, wanted to be so much like his peers that he refused school services. Yet, refusing support did not increase his acceptance among his peers. Ashton's body was found in a wooded area. His inability to communicate with others and their lack of understanding of his needs pushed Ashton to the point of suicide. It seemed that Ashton's pain became too much to bear. Both young men tried to fit in, but were denied access into the social world of adolescence. Each person had difficulty figuring out social conventions for "fitting in." In the case of Ashton, it became too much to cope with so he ended his life. They lived in a world different from others.

What is the big deal about fitting in anyway? Why should I be like someone else? What's in it for me? Isolation, fear of ridicule, and inadequacy are some reasons to conform to peer pressure (Lashbrook, 2000). However, for people with Asperger's Syndrome, fitting in is not as easily obtained as for their neurotypical peers.

From an early age the experience of feeling 'different' was very real to some of these young people. Those with Asperger's Syndrome highlighted the pain of feeling different from others on many occasions. It is this inner awareness of difference that for some can make living with Asperger Syndrome so difficult. For those with Asperger Syndrome, the self-'perception' of being different and feelings of inadequacy were described as being a major cause of inner pain and suffering. The usual pleasures of socializing, of friendships and close relationships seemed to be denied to them, yet the desire to be like other people was intense. They saw their peers 'joining in' and seemingly enjoying the company of others, and many wanted to be able to join in too. (Portway & Johnson, 2003, p. 439)

Feeling different is an ongoing issue for people with Asperger's Syndrome. Even when they try to fit into the social arena, their needs often are misread, pushing them back into outsider status. It takes a person with Asperger's Syndrome longer to build a rapport with society. Barnhill (2001) writes, "The key problem is not that they are socially isolated but they cannot change their behavior to the environmental demands" (p. 261). What has happened to giving people a chance? Where are the virtues of patience and understanding of others? What measures does one take to fit in? Is fitting in really worth the effort if ridicule is the consequence for one's attempt? And, whose values and criteria prevail as norms for inclusion?

While reflecting on my experiences with students with Asperger's Syndrome, I recall a neighbor who had fraternal twin boys, Jim and Tom. During their infancy, neighbors only saw

Tom. I thought this was strange and inquired, “What’s wrong with Jim?” Of course, I was told that Jim was sick. When the twins were about five years old, it was obvious that they lived in two different worlds. Tom was an active and rambunctious young child. Jim, on the other hand, did not behave like his brother or other five-year-olds I knew. He was very sedentary, and constantly smiled for no apparent reason. Jim entertained himself by sitting on the porch staring into the blue sky, while engaging in self-stimulating finger play for what seemed like hours. Neither the harshest force of the north wind nor the hottest days of summer kept Jim from sitting on the porch. What was both fascinating and frightening was observing Jim catch a bumblebee while in flight, without tearing its wings or being stung. Loud warnings from neighbors, out of concern for Jim’s safety, seemed inaudible when a winged insect was his focus. He did not initiate or participate in play activities with other children, even when he was invited to join in childhood games. Jim engaged in solitary play activities unlike any child I knew.

### *Difference of Opinion*

When I have a conversation with others about my interest in Asperger’s Syndrome, they often visualize a person like Jim. They were familiar with the character Dustin Hoffman portrays in the movie, *Rain Man*, and associate this character with autism. However, they were not familiar with the many traits of Asperger’s Syndrome. Why do some people think that a person either has intelligence or a disability? Why is it so hard to believe that a person can have both? What does this dichotomous naming mean for persons with disabilities? Williams (2001) writes, “Children with AS usually have average to above-average intelligence (especially in the verbal sphere) but lack the higher level thinking and comprehension skills. They tend to be very literal: Their images are concrete, and abstraction is poor” (p. 290). Comprehension becomes a problem when the material is not factual (Myles et al., 2001). Safran (2002) notes, “With average to superior intellectual capacity, the child with Asperger’s looks typical but lacks the social awareness and skills needed to connect with his or her world” (p. 60).

I realize questions posed by others might be due to their misunderstanding of Asperger’s Syndrome. People are not aware of all of the characteristics that make these individuals so unique. *The Merriam-Webster Online Dictionary* (2003) defines unique, as being derived from the Latin word *unicus*, from *unus* one, meaning “being without a like or equal.” We all possess characteristics that make us unique individuals. Yet, comments regarding people with Asperger’s

Syndrome are focused on the behavior or the mental state of the individual. There is very little attention given to the person with Asperger's. What stands behind the fear or avoidance of persons with Asperger's Syndrome?

It's funny because Asperger's syndrome is not like autism, it is a subdivision sure but in essence when you think about perception wise and the pain, the real severity of the pain that individuals will go through, it is the opposite. I think that autistic people are in a world of their own, they are oblivious to things that go on outside them and so they are contented with the way they are, this is what I think. And you know I wish I was like that, in terms of affliction, in terms of the depths that you go to, the emotional depths that you go to in Asperger's is a lot more, mm, deadly. (William, as cited in Portway & Johnson, 2003, p. 439)

William speaks about Asperger's Syndrome as if it is a terminal disease. What did he experience to make him reach this conclusion? What is his world really like? Although Asperger's Syndrome is not contagious, some people may treat it as if it were an infectious disease. Differences are visible. When in a crowd, people with Asperger's Syndrome may make a comment that some people may find offensive, or monopolize a conversation to the point that people leave the circle. Is it possible that a person with Asperger's Syndrome reminds others of the charades they play so well? Searing honesty might be difficult to accept.

### *Seeing is Believing*

Insight is more than the knowledge of this or that situation. It always involves an escape from something that had deceived us and held us captive. (Gadamer, 1975/2003, p. 356)

This quote speaks to the insight others may have had regarding autism. *The Merriam-Webster Online Dictionary* (2003) defines insight as "the act or result of apprehending the inner nature of things or of seeing intuitively."

When I met Mark whom I introduced in Chapter One, his persona drew me in; he caught my attention and I wanted to know more about this young man. Mark has Asperger's Syndrome. After further research into the disorder, I discovered that Asperger's Syndrome falls on the Autism Spectrum. When I shared this new research interest with others, I was surprised by the response. I received looks of concern. I was asked the following questions: "Why would you put

energy into people with intellectual ability? If they are that smart, why can't they behave? Why should society change for a small group of people who lack social skills? Why are you working with intelligent people? I thought you were a special education teacher.”

### Sixty Years and Counting: Still Looking for Answers

Sixty years after Hans Asperger, a Viennese physician, conducted a study on four patients, his work is resurfacing on the syndrome that carries his name. Asperger's Syndrome was discovered in 1944. Hans Asperger published a paper that described four young boys considered having personality disorders due to their abnormal abilities and behaviors (Barnhill et al., 2002; Myles et al., 2001). Lorna Wing's research revealed two points about early development that was not noted in Asperger's study.

First, he states that speech develops before walking, and refers to 'an especially intimate relationship with language' and 'highly sophisticated linguistic skills' ...However, slightly less than half of the present author's more typical cases of Asperger's syndrome were walking at the usual age, but were slow to talk. (Wing, 1981, p.117)

Secondly, Asperger described people with his syndrome as capable of originality and creativity in their chosen field. It would be more true to say that their thought processes are confined to a narrow, pedantic, literal, but logical chain of reasoning. (Wing, 1981, p. 118)

Her work gained recognition in the medical profession as well as the public at large. Yet, it was still sometime before Asperger's Syndrome received recognition in the *Diagnostic and Statistical Manual for Mental Disorders* in 1994.

In Asperger's paper, *Die 'Autistischen Psychopathen' im Kindersalter* [*Autistic Psychopathy in Childhood*] (1944/1991) translated into English by Firth, he mentions a Swiss psychiatrist Eugen Bleuler who coined the terms autism and schizophrenia, both of which relate to a person's limited interaction with their environment. Asperger (1944/1991) writes, "Essential symptoms of schizophrenia and the symptoms of our children can thus be brought under a common denominator: the shutting-off of relations between self and the outside world. However, unlike schizophrenic patients, our children do not show a disintegration of personality. They are therefore not psychotic, instead they show a greater or lesser degree of psychopathy" (p. 39).

Asperger's four patients presented a different face of the syndrome.

Some researchers view Asperger Syndrome as a separate clinical entity to Autism, others describe it as a sub-group of Autism, or part of the spectrum or continuum of difficulties, and yet others do not use the term Asperger Syndrome at all. (Greenway, 2000, p. 470)

Individuals with Asperger's often demonstrate behaviors that most people consider bizarre or offensive in mainstream society (Willey, 2001). Initiating a conversation or understanding social cues is commonly difficult for people with Asperger's Syndrome. Leichman (2003) writes, "Susan Meyer is 28 years old, and she's never had a friend. It's not hard to figure out why. If you talk about a topic that bores her, she can't feign interest. If you tell a joke, she won't get it. When she gets started on one of her favorite subjects – miniatures or medieval legends – she can go on for hours" (p. F01). It is a challenge for them to establish relationships with peers, empathize, or see another's point of view. People with Asperger's Syndrome often have sensory sensitivity to smells, textures, and noise (Andron, 2001; Asperger, 1944/1991). Understanding these sensitivities, as well as their causes, helps others to be able to respond more insightfully.

### *Causes of Asperger's Syndrome*

If you were to ask three people about the causes of Asperger's Syndrome, you would hear three different answers. There are many theories about its origin. Some of the theories include Measles, Mumps, and Rubella (MMR) vaccine, lack of attention from the mother, high levels of testosterone in the womb, and genetics.

Autism is due to a specific brain abnormality. The origin of the abnormality can be any one of three general cases: genetic fault, brain insult or brain disease. Autism is a developmental disorder, and therefore its behavioral magnifications vary with age and ability. Its core features present in different forms at all stages of development and at all levels of ability, are impairments in socialization, communication and imagination. (Frith, 1991, p. 2)

As a child, Einstein was a loner, and repeated sentences obsessively until he was 7 years old. He became a notoriously confusing lecturer. And despite the fact that he made intimate friends, had numerous affairs and was outspoken on political issues, Barron-

Cohen suspects that he too shows signs of Asperger's Syndrome. "Passion, falling in love and standing up for justice are all perfectly compatible with Asperger syndrome," he says. What most people with AS find difficult is casual chatting—they can't do small talk. (Muir, 2003, p. 10)

Although it was not proven that Einstein had Asperger's Syndrome, his behavior raises suspicions. Some people may demonstrate characteristics of Asperger's; nonetheless, it does not mean that everyone who has eccentric behavior has Asperger's. When I speak with parents whose children were diagnosed with Asperger's as adults, they tend to recall odd behaviors from childhood. After the diagnosis or naming, things seem to make sense to both the parent and adult child. They then have to decide, "What does this mean? Where do they go from there?" For some, it presents more confusion.

A 60-year-old researcher, Dr. W., was referred because of persistent problems at work. He had been married, and had grown-up children. He had worked for many years as a social worker and social work teacher. His problems at work had come about because of his lack of diplomacy, and his apparent lack of empathy. He said of himself, 'I know how to go through the motions of sympathizing with someone, but I don't feel it.' His wife said that he could not adapt his behavior to hers, that he had genuine difficulty in knowing how she was feeling, and that she could not tell how he was feeling from his face or tone of voice. Sometimes she would say, 'Just act as if you are interested. That would be enough', but he could not pretend to feel something that he did not. Dr. W. described himself as being often anxious, but had no autonomic symptoms. He had never had OCD. His interests were esoteric, but not eccentric. He enjoyed the company of people he knew well, and was capable of a great deal of warmth. (Tantam, 2000, p. 55)

Dr. W. appeared able to navigate through most of his life, but it seems that empathy was problematic in his professional life. His wife shares that her husband could not read her feelings. Surely, Dr. W's esoteric interests and lack of diplomacy did not begin in adulthood. I wonder about his childhood experiences. What was he like in elementary, middle, and high schools? Did the teachers notice anything about him? What was his playground or gym class experience like? What was his college experience like? Did he develop friendships during his early years? Did the

lack of diplomacy increase as Dr. W. reached adulthood, or was he always unable to demonstrate diplomacy. How did he meet his wife? What was he like as a father? How much of a role does his wife play in his social life? Dr. W. appears to be successful in his adult life. He earned a doctorate degree, had a career, and a family. I cannot help but wonder if Dr. W., his wife, or another family member read an article or saw a story that struck a chord regarding his behavior. Surely, he has been like that for most of his life. What makes him so different at age 60? What made Dr. W. seek out a diagnosis? What did the diagnosis mean to him and his family? The next section looks at the criteria for Asperger's Syndrome as defined by the American Psychiatric Association.

### *Criteria for Diagnosing of Asperger's Syndrome*

The diagnosis of Asperger's Syndrome is determined by the *Diagnostic and Statistical Manual for Mental Disorders* (DSM-IV), fourth edition (American Psychiatric Association, 2003). The first criterion identified is a qualitative impairment in social integration which must include two of three traits. Those traits include marked delays in nonverbal behavior such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction. A second trait is a failure to develop peer relationships appropriate to development level. The third trait is a lack of spontaneous seeking to share enjoyment, interests, or achievements with others (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people).

The second criterion involves restricted areas of interests, and stereotypical behaviors and activities. One of four traits must be present: preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus; inflexible adherence to specific, nonfunctional routines or rituals; stereotypical and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements); or persistent preoccupations with parts or objects.

A third criterion is that disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning. A fourth criterion is that a person demonstrates no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years). A fifth trait is that there is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in

childhood. Finally, criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia (American Psychiatric Association, 1994, p. 77).

The criteria for Asperger's Syndrome read like a recipe. The list contains the ingredients that complete the recipe. It seems that any child could possibly demonstrate these traits during the developmental years. Each trait is generally used when interacting with others in a social climate. Behaviors that most of us engage in such as eye contact, facial expression, posture, and gestures in social situations often prove to be a difficult task for people with Asperger's Syndrome. To go a step further, imagine what life would be like if you were unable to develop a relationship with another person. I wonder how parents interpret this list. Do the criteria paint a grim future for a person who receives this diagnosis?

Many students with Asperger's Syndrome are receiving general education with their non-disabled peers. In order for them to receive support, they must be found eligible to receive special education services. If students with Asperger's Syndrome are found eligible to receive special education services, they can access a range of support. Still socialization among their peers continues to be an impenetrable force for this population.

### *Labels, Labels, Labels*

It seems that when disability and intelligence are dealt with as two separate entities, they are more acceptable. However, when disability and intelligence are found in the same person, there seems to be a sense of disbelief. Why does it seem so strange? The reasons behind this may lie in a few definitions. *The Merriam-Webster Online Dictionary* (2003) defines dis- as Middle English *dis-*, from Latin *dis-*, literally, meaning "apart, and to do the opposite of." Disable means "to make incapable or ineffective, to deprive of physical moral or intellectual strength," and "able" from the Latin words *habilis apt*, from *habere*, means "to have means having a sufficient power, skill, or resources to accomplish an objective." The same source identifies intelligence from the Latin words *intelligentsia*, from *intelligent-*, *intelligens*, which means "the ability to learn or understand or to deal with new or trying situations."

People with Asperger's have difficulty adjusting to new situations (Asperger, 1944/1991; Barnhill, 2001). Temple Grandin is a good example of a person with both disability and intelligence. Grandin is an adult living with High-Functioning Autism. She earned a Ph.D. in animal science and published numerous articles and books. Grandin is a consultant who designs

livestock facilities (Happe, 1991). Having High-Functioning Autism did not hinder her from learning and accomplishing goals. Grandin will have challenges along the way, but she remains open to new situations.

Disabilities and intelligence are two separate continua. Both disability and intelligence are labels used to describe individuals. Intelligence is often a celebrated event, and this label generally brings acceptance, pleasure and usually opens the door to a promising future. Wearing this label moves individuals to front line status, no waiting at all. Disabilities often are not celebrated. In fact, disabilities may be kept a secret. This secret is hidden like a precious family keepsake in wardrobes, desk drawers, or chests, out of the reach and view of others.

A wardrobe's inner space is also intimate space, space that is not open to just anyone. Out of sight, out of mind. (Bachelard, 1964/1994, p. 78)

Wardrobes with their shelves, desks with their drawers, and chests with their false bottoms are veritable organs of the secret psychological life. (Bachelard, 1964/1994, p. 78)

These quotes speak about spaces that children and youth with disabilities involuntarily occupied before laws were passed to protect their rights. When I think about desks, drawers, and wardrobes, I see them as places to keep valuables, not unwanted items. Even a junk draw holds valuable items. In the past, some homes, schools, and institutions were pieces of furniture that stored individuals with disabilities. These pieces of furniture locked individuals with disabilities in secret nooks away from society.

Before Public Law 94-142, the Education for All Handicapped Children Act of 1975, became law, children and youth with disabilities were family secrets. In the past, institutions overflowed with people who did not fit the normal bell curve much like Hans Asperger's four patients. They were the secrets kept in our wardrobes, desk drawers, and chests. Today, children and youth with disabilities are protected by laws, and are no longer hidden from the public eye. Unfortunately, many students and families fight the labels established to protect children and provide an appropriate education.

A thing as everyone thinks he knows is that around which the properties have assembled. We speak in this connection of the core of things. The Greeks are supposed to called it *hupokeimenon*. For them, this core of the thing was something lying at the ground of the

thing, something already there. The characteristics, however, are called *ta sumbebekota*, that which has always turned up already along with the given core and occurs along with it. (Heidegger, 1971, p. 22)

Heidegger's quote speaks to the core of things. Because a person has Asperger's, does not mean their core is defined by these characteristics alone. Personal characteristics make them a unique person like anyone else. Their inabilities do not eliminate who they are; they will always be a part of that core.

The inability to communicate and socialize with others is characteristic of Asperger's. I knew that Asperger's Syndrome was a phenomenon worth pursuing, as there appears to be a lack of knowledge about this population, which often leads to misunderstanding. As a Special Education professional, my interest is to help others understand Asperger's Syndrome. I seek to be a voice for these special people and their abilities. In my journey toward understanding the world of Asperger's Syndrome, I travel to the heart of the phenomenon: the experiences of students with Asperger's Syndrome. What might their experiences teach us? What might we do with these learnings?

When I began working with students having Asperger's Syndrome, I observed that their experiences were quite different from Jim's whom I introduced in Chapter One. These students do not catch bumblebees, but, like Jim, they are held prisoners in a socially dependent society. In an effort to assist students to transition into adulthood, it is crucial that these young people do not become invisible in the communities where they live, play, and work. Students are entitled to receive a variety of supports until the age of 22, as mandated by the Individuals with Disabilities Education Act, 1997. Many times, students with Asperger's Syndrome may be educated in mainstream classes. The mainstream can be a lonely place for students who do not fit in, especially when the students do not behave or dress according to the standards of their peers. In what way might we begin to question our normative standards? What is the determining factor for deciding a person's place?

Portway and Johnson (2003) write, "School life became more and more difficult as they became older, and this seemed to be related to the increasing social expectations from the children themselves as well from peers, teachers, parents, and society in general" (p. 438). Students with Asperger's have difficulty finding their place among the many social demands

found in a school setting. They often ride the merry-go-round and find themselves disoriented long after the ride is over. They stick out like a bull's-eye and often are vulnerable to ill treatment among peers. According to Frith (1989), "Autistic children are often badly teased and tormented by their normal peers. This suggests that the social oddness of autistic individuals is so outstanding that no physical sign is needed to brand them as outcasts" (p. 139). Casey (1993) opens his book, *Getting Back into Place*, with this question:

Can you imagine what it would be like if there were no places in the world? Being guarantees Place. (pp. ix-x)

Who would we be without place? How would we survive in the world if we did not have a place to claim, to call our own? Would this mean disappearing into vast nothingness? Would we disappear into the landscape of the world? "If being guarantees Place," then how is it possible that others can determine where one's place should be? Why should one person determine how and where another fits? People with Asperger's Syndrome, like other citizens in the community, should have the opportunity to enjoy a quality of life without ridicule or avoidance. They may behave in a manner that makes others feel uncomfortable in certain situations. I am sure everyone can share an experience or two about such situations in our lives. Usually, it warrants understanding, not excommunication. "They are just being themselves," is what our parents told us growing up. What would it be like if you were not allowed to be yourself? Life would be played out like a game of charades in order to shield one's true self. People with Asperger's are genuine in their presentation of themselves. They may not present themselves in a way that others agree with, but they wear no masks. They do not apologize for being themselves. They are who they are, themselves. The following experiences show people with Asperger's being themselves. There is no script or coach to help them along. Listen closely.

#### *A Catch-22 in the Halls of Higher Learning*

When a person has a disability, he or she may face the difficult choice of whether or not to disclose to employers. Usually, a person discloses a disability when accommodations are necessary to perform a job successfully. Often, people with a disability find themselves in a catch-22. Should they disclose or remain silent? Diament (2005) writes about adults with Asperger's Syndrome employed in colleges and universities. Some professors disclosed their

disability, while some decided to remain quiet. Here are a few experiences of adults with Asperger's Syndrome who work in the classrooms of higher education.

*Lars.* Lars Perner is a professor of marketing who has Asperger's Syndrome. He knows all too well about the challenges one encounters in the interview process. He was in search of a tenured track position at a college or university. Diament (2005) shares that "In 2001 Lars Perner had been hired to three visiting-professor positions without having set foot on the campuses" (p. A10). Yet, he was unsuccessful on twenty-five face-to-face interviews at various institutes of higher learning. He could not understand why he was not selected for a position he knew he was qualified to perform. He thought that he did well in the interviews. After some thought, Lars chose to disclose his disability in advance. Although disclosing was a risky thing to do, the decision resulted in his acquiring a position as an assistant professor of marketing at the Imperial Valley campus of San Diego State University. Lars believes that disclosure was the right thing for him to do in order to acquire employment.

*Dawn.* Dawn Prince-Hughes is an anthropologist who has Asperger's Syndrome. According to Diament (2005), Dawn has certainly had her share of challenges of not fitting in over the years. As a sophomore, Dawn dropped out of school, experienced being homeless and even worked as an exotic dancer before she found her niche. Dawn became intrigued with gorillas on a visit to the zoo. This visit started her on a journey into the field of anthropology. Dawn found that disclosure did not hurt her chances of getting a position as a researcher. Over the years, she learned how to adjust in the social world by not prying into others' personal lives and being open with her disability.

The experiences of Lars and Dawn demonstrate that being open with employers about a disability opens the door to employment opportunities. Nonetheless, not everyone takes the same attitude about disclosure. An unnamed visiting professor of astronomy and physics works at a college in Pennsylvania. He, too, has Asperger's Syndrome. However, he chose not to disclose his disability out of fear that the information would hurt his chances for employment. He decided to keep his disability a secret, which resulted in a continued hunt for a tenure position within the walls of higher learning.

According to Diament (2005), the higher education environment can be more accepting of people with autism. In fact, she feels that the higher education environment is a place where a

person with Autism can be themselves and use their special talents without ridicule. Yet, she found other professors with Asperger's Syndrome who still refuse to disclose for fear of being treated differently by colleagues. What makes some people disclose and others keep it a secret? It is a difficult choice to make.

### All Aboard

As I continue to work with students identified as having Asperger's Syndrome, I discover the depth of their disability and the services these students will require in order to become productive and active citizens in the community. I gave a presentation to a 9<sup>th</sup> grade class that included students with autism. During my presentation, I shared with them the kind of services that I provide during the high school years. One student raised his hand. When I acknowledged his presence, he stood up and said, "Hi, my name is Frank, I like airplanes. Can you get me a job at the airport?" This student gave a brief history of airports, as well as the various job opportunities that he could perform when he reaches the age to work. In fact, his entire conversation was centered on airports. Frank wanted to continue talking, but the grunts from his classmates and my desire to hear from the other students, caused him to shorten his conversation. I told Frank that I wanted to hear more about his interest at another time. Looking pleased, he smiled and sat down, and then I continued the presentation.

I began to think about Frank's knowledge of airports, and his excitement about the possibility of working at such a large and crowded place. Will Frank be overwhelmed by all the changes that occur at an airport? In addition, I think about the contribution he could make as a worker. What does the airport mean to him? Is the airport just an interest, or does he really want to seek employment? I wonder how others would perceive him in such a work setting. Will the workers and passengers welcome Frank or ignore him? What will a smile mean to him in such a busy place? I think Frank is just being himself. How will his be-ing-ness play out at such a transient place where people from around the globe pass through on a daily basis? Frith (1989) writes:

Autistic individuals cannot 'read between the lines' to know whether or not they are welcomed, or they may panic when suddenly faced with an unfamiliar requirement. For example, a young woman who is employed, lives independently and drives her own car, regressed completely when her car broke down, showing stereotyped speech and hand

flapping. (p. 140)

This kind of behavior would call attention to a person working in a busy environment. Will the employer show tolerance for such behavior? I had a conversation with Mary, a teacher who works with students across the Autism Spectrum. During our conversation, Mary shares her experience working with these students.

Teaching social skills is important. Practice, practice, practice. Practice is essential for students on the Autism Spectrum to learn proper social skills. Students need to practice how to behave in various settings before they leave high school. (Mary)

I can agree that students need numerous opportunities to practice taking acceptable social skills to a variety of settings. Adjusting to change as it occurs will require practice as well. Life involves many changes. In school, we experience fire drills, power outages, weather delays, and other emergencies that force us to change our daily routines. These same kinds of emergencies occur in the community. Students with Asperger's must be able to demonstrate flexibility when these situations occur. It is pertinent to prepare students to cope with change, in many forms. One student experienced this type of situation on the job.

The following is an experience of a young man who had the ability to do the job, but lacked the social nuances needed to fit into a social circle. When Phillip arrived at work, he changed into his work smock and prepared for his shift. As he began work, the assistant manager stopped by Phillip's station and asked him to stock the salad section when he was done. When Phillip finished stocking the fruit bin, he stopped by the manager's office. The assistant manager told Phillip that the manager was in an all day meeting and would not be returning until the next day. The assistant manager asked Phillip if he had stocked the salad section. Phillip told the assistant manager that he was only supposed to stock the fruit section. The assistant manager went on to tell Phillip that he needed his help in the salad section. Phillip told the assistant manager that he was assigned the fruit section and refused to stock the salad section. When Phillip left the office, he continued to stock fruit bins for the rest of his shift, and ignored the assistant manager's order. Phillip was acclimated to the routine of stocking the fruit section and that is exactly what he continued to do. Phillip's display of inflexibility is usual for many people with Asperger's Syndrome. He was set on stocking the fruit bins and nothing else; that was his

job and he did not believe that doing any other task was an option. Phillip did not follow the order of his second-line supervisor. In fact, he continued with his normal routine. The insubordinate behavior Phillip demonstrated with the assistant manager is one reason people with Asperger's Syndrome may lose their jobs. Yet, for individuals like Phillip, changes made to the routine cause conflict.

Muller et al. (2003) write, "Individuals with ASD have difficulty adapting to novel situations and routines, and often tend to shy away from new experiences because they find them both emotionally and cognitively taxing" (p. 168). It seemed that Phillip became so comfortable stocking the fruit bins that the request to perform another task proved to be overwhelming. Stocking the salad bins may seem like a simple request that many of us may take for granted, but this request was a major issue for Phillip. This request interrupted his normal routine. Is it possible that Phillip misread his duties and only expects to stock fruit? What will Phillip do when his supervisor requests him to perform other tasks within the store?

I often think of Mark, the student mentioned in Chapter One. He was unable to navigate his social world at school and within the community. He longed for a place of his own. I often watched him wander through the building looking for his place among a sea of beings who shared a common space. He moved through the hallways like the character Patrick Swayze portrayed in the movie, *Ghost*, who as a spirit went unnoticed. He was transparent, a blank space to those around him. Mark's search often ended with little or no acknowledgment from the other students. What must it have been like for Mark on his quest to find acceptance in such unfriendly waters? What does it mean to be accepted? *The Merriam-Webster Online Dictionary* (2003) defines accept as being from Middle English, from Middle French *accepter*, from Latin *acceptare*, meaning "to give admittance or approval." It is hard to believe that one can be among so many people and not be accepted. Acceptance is like a gate; some are made to swing freely to allow admittance to all, while others are made to lock, thus blocking admittance.

### *Concerned Families*

As a teacher, I experience concern and frustration as I assist students with Asperger's Syndrome transition into adulthood. The challenge is getting others to see the students' abilities rather than their idiosyncrasies. *The Merriam-Webster Online Dictionary* (2003) defines transition as "a movement, development, or evolution from one form, stage, or style to another."

Life brings about many transitions, and adults must learn to cope effectively with transitions that occur during their life span, whether anticipated or unanticipated (Merriam & Caffarella, 1999). A student's inability to socialize is a barrier to successful transition, and often has a negative impact on their quality of life in adulthood.

Unsuccessful transition is a concern for parents, too. Families have their share of challenges raising a child with Asperger's Syndrome. When families decide to have children, both parents look for ten fingers and toes. They wonder what their child will be like as a toddler, a teen, then an adult. What do parents do when a child does not respond to their affection? What must it be like for parents when their child will not be able to reciprocate affection? What must this disconnection be like for the child? A trip to the playground can be a lonely experience. Why does my child choose to play alone? Why do other children bypass my child?

Portway and Johnson (2003) conducted a study with 25 families to get the perspective of adults with Asperger's Syndrome (from 18-35 years) and their parents to determine their life experiences. The study concentrated on what it was like for people growing up with Asperger's Syndrome. I share the interviews from both the parents and adults as they describe their experiences with Asperger's Syndrome. Listen closely.

### *A Labor of Love*

Parents of children with Asperger's Syndrome put much effort into helping their child fit into social circles. The first social circle is the family. Parents often do whatever is necessary to make their child feel loved and be comfortable within the family structure. Parents will go through great lengths to soothe their child when they are sick, lonely, sad or in need of support. One mother shares the length she went to make her child comfortable:

From a little baby he would refuse to suck on anything other than a yellow dummy, it had to be yellow or he would scream for ages...and so I ended up buying yellow dummy's wherever I could get them so I wouldn't run out of them, not to have a yellow dummy was hell. (Portway & Johnson, 2003, p. 437)

Traditionally, parents used a pacifier or bottle nipple stuffed with cotton to soothe the baby. Well, a pacifier and nipple were no match for a yellow dummy. What makes this yellow dummy the choice to soothe his oral fixation? What is the shape of this dummy? Would another

color, say red, satisfy him? What makes the yellow dummy more satisfying than a pacifier? What is a parent to do? This mother decided that the yellow dummy made her more peaceful.

Usually, when all else fails, holding the baby acts as a soothing method. Holding, rocking, or walking a baby does the trick when all else fails. The warmth of the body provides a sense of security. Imagine a baby being resistant to close proximity and nurturing of a parent. Portway and Johnson (2003) interviewed a father who was faced with this dilemma. The father commented, "If she was upset it would be no good cuddling her, she would prefer to be put down and left alone" (p. 437). What is it like for a parent when the child detaches herself from affection and security? What is it like for parents to leave their child alone not knowing if they are in distress?

Beginning with the immediate family, parents work hard to help their child socialize with siblings and other relatives. The ultimate test comes when their child is able to transfer social skills when interacting with their peers. It breaks a parent's heart when other children do not receive their child. Portway and Johnson (2003) interviewed parents who shared their experience:

Stephen was rarely invited to birthday parties and he never wanted one of his own, he was my little loner. (p. 438)

With Phillip we were always trying to put a square peg into a round hole. If the hole was big enough he would fall right through without being noticed, if it was too small he wouldn't get anywhere, often he could be forced in, but it was always an uncomfortable fit, whatever he would always end up being hurt. (p. 440)

A birthday party is a large social event for children. Parents have the opportunity to watch their child interact with peers. Sounds of laughter and singing fill the air. Parents enjoy watching their child fit in. Stephen's mother has not experienced her son's laughter at parties because he is not invited to birthday parties, nor does he want to have one of his own. Phillip's father says that his son does not fit into any situation. What is it like for parents when their child does not fit in? I wonder how many attempts were made to engage both Phillip and Stephen in social events.

## *Searching for the Right Fit*

Friendship is an important part of life. Friendships usually develop during the early years, especially in school. Imagine not being able to fit in or develop any friendships among your peers. People with Asperger's Syndrome live with that dilemma daily. Sometimes, the experience can be so uncomfortable that the person chooses to remain alone. Portway and Johnson (2003) interviewed adults with Asperger's Syndrome about their school experience. They did not fit in with their peers and expressed what that experience was like for them. The following stories reveal the painfulness of not fitting-in for a child.

*Rachel.* "I was sick every morning before I had to go. My father was so strict; he wanted me to get there and would drag me into the car. One morning we got there and I didn't get out and he shouted. I still wouldn't get out so he drove to work and I stayed in the car while he was at work all day... So then I had to see another educational psychologist who said I had to go to school. I burst into tears because I just couldn't do it." (Portway & Johnson, 2003, p. 439)

The thought of school made Rachel physically ill. Each morning she challenged her father about going to school. Each day Rachel left the house kicking and screaming. Why was school such a negative place to be? Did her peers reject her? I wonder how she behaved once she arrived at school. Did she just settle down into her lessons? Did the sick feeling go away? How long did Rachel go through this ritual?

*Sebastian.* "I would often stand in the playground or sit in class and just watch others...playing together, talking, laughing, joking—having fun, I wished I could join in or have a special friend but I never really did, I would usually be on my own, just like an outsider looking in." (Portway & Johnson, 2003, p. 439)

Sebastian, unlike Rachel, wanted to be at school and interact with his peers. He was among his peers but did not initiate interaction with them. He considered himself an outsider on the playground and in the class. It is strange that a teacher did not notice Sebastian's loner status on the playground and the classroom. What was his experience like in middle and high school? His story is so common. He wanted to be a part, but excluded himself.

*Ben.* "I remember feeling quite uncomfortable around people, straight away I realised I was not right, it was just a sort of vague uncomfortable feeling that grew as I grew." (Portway & Johnson, 2003, p. 439)

I wonder when Ben began to feel uncomfortable in the presence of people. Is this feeling induced by anxiety? Does Ben's uneasy feeling occur when he is in large places like a store? Does he feel different around family? When he said, "I realised I was not right," it made me believe that given the right situation, Ben may interact with others.

The findings in Portway and Johnson's study show that people with Asperger's Syndrome feel they do not fit in. Although they may look like their peers, they are marked as different. If you listen closely to the interviews, you can discover a lot from both the parents and the adult with Asperger's Syndrome. When you listen closely to the parents, you can hear their pain and frustration. Parenting is a big job. Some days are filled with joy and happiness, while other days are filled with many challenges. What happens when your days have more challenges than joy? The scales become unbalanced. One may begin to ask many questions: How can this be? Why me? I think about the experiences of the parents and wonder what their social life was like? The mother whose child only accepts the yellow dummy must have been very frustrated. What does the yellow dummy mean to the child?

Willey (2001) added her daughter's choice of colors throughout their home to make everyone's life a little easier. When a baby is sick, hungry, or in need of changing, he or she will cry. It would be difficult for a parent to know if the baby is in need when the baby is silent. This can be frustrating as well as unhealthy, because as a parent, you are clueless to their wellness. One parent reflecting on her son's inability to socialize states:

In junior high, well, I think that's an age when kids are so intolerant of differences... there's always been one or two kids that he felt were really giving him a bad time...and then there's all this going from one class to another, all the noise and confusion, I think really unsettles him. And then the whole puberty thing and the hormones. Seventh and eighth grade have been difficult, he's really had a lot of anxiety, a lot of depression, a lot of ups and downs.... When he hit puberty and started noticing the opposite sex, he really realized that he has had a hard time knowing how to socialize and he said that he felt bad that other kids seemed to know how to talk to kids and how to talk to girls, and he just didn't know how to do it. (Marks, & Schrader, 1999, p. 56)

This reflection is a common concern of parents. They want their children to make friends and are concerned when other children do not accept them. In middle school, students still are

searching for their identities; unlike middle school, high school has a different set of norms. Davies (1999) writes, “Social reputation becomes important during the middle years, as children begin to reflect on their status in the group. School-age children are increasingly aware of how others see them” (p. 306). Popularity rules at this level. Academic excellence and extracurricular activities like sports and social organizations may determine a student's place in the high school social scene. Imagine not being able to fit into any of these categories. Preto (1999) writes, “Their values and beliefs about life, their views about gender relationships, the way they dress, talk, and walk are all greatly influenced by what they see on TV and in films and the music they hear” (p. 275). Homecoming dances, choice of music, sporting events, the senior prom, and other social activities may not be part of their high school memories. Students are aware of skin condition, style of dress, moreover, the importance of friendships at this age. They want to look and behave like other students. They work hard not to stick out among their peers like a banana, unless yellow is the color of the day. As a parent and educator, I understand the importance of children having friends. Parents cannot be with their children every minute of the day, but desire that their children have healthy and positive social experiences with their peers. Still, the challenge for parents and educators alike is for students with Asperger’s Syndrome to develop socially.

### Body Talk

Even though I know you and even though we share something in common, nevertheless I chose to behave as if I am so different from you that this particular difference is enough to snub you. (van Manen & Levering, 1996, p. 81)

In this quote by van Manen and Levering, the communication demonstrated is by choice. According to van Manen and Levering (1996), this secret body language is called Physiognomy. It is defined as “the phenomenon of external, visible, physical signs that somehow betray inner feelings, thoughts, or character traits” (p. 78). Although a person acknowledges commonalities, the choice is made to snub, or exclude another person. This is a concern especially since people with Asperger's lack the ability to read such body language. Goffman (1963) discusses two kinds of communication: “expressions given” and “expressions given off” (p. 4). People with Asperger’s Syndrome do not have practical understanding when it comes to reading the body

language of other people. Mark did not read the boundaries of a closed door. To him a closed door seemed to be just an object to pass through to reach a destination. Mark's inability to interpret body language may not only lead to exclusion, but it can present a legal and safety issue.

Another dimension of "body talk" is the proximity one can get to another in talking without invading personal space. If you were to ask people about proximity, you would get many answers among the diverse cultures that make up our community. How close can a person get to another before an uncomfortable feeling takes over? What does closeness mean to some people? When communicating with another person, what does a person consider a safe distance? Living in the days of harassment and zero tolerance in school, on the job, and within the community, proximity cannot be taken lightly. One has to know the boundary lines. Individuals with Asperger's have challenges reading such boundaries.

Sometimes, the expressions given off by students with Asperger's are misread. One day I saw Frank in the hall. He walked towards me, stopping just short of touching my body with his and said, "Hello." There was little space between us and he did not appear to be bothered by such close proximity. I carefully moved back and greeted Frank. As he attempted to move closer, I said, "You should not stand so close to a person when you are speaking with them unless you are given permission to move closer." Some people may feel uncomfortable and even awkward when others stand too close to them. He said, "Did you feel uncomfortable?" I answered, "No, but I want you to practice keeping a comfortable distance when talking with others." Without asking, Frank demonstrated what he thought was a comfortable social distance. "You did a great job, keep up the good work," I commented. Frank said, "Okay" and walked on to his class. Will Frank remember the comfortable distance that he should place between himself and others? What will our next encounter be like? Will another person ask him politely? As I watched him move through the hall, I wondered if he would demonstrate comfortable social distance with others. I did not react; instead, I talked with Frank about maintaining a comfortable social distance. I exercised what van Manen and Levering (1996) call "pedagogical tact" (p. 115). It is so important not to make Frank feel as if he did something wrong. Instead, I wanted Frank to be able to transfer this skill of using the proper social distance when meeting others.

## Canvassing One's Essence

I witness the expressions given off, the expressions given, and the reactions on the faces of both students and adults when they encounter a student with Asperger's Syndrome. The facial expression usually conveys a look of uncertainty. The expressions also seem to communicate a request for assistance. We cannot shield students with Asperger's Syndrome from the world. It is important for them to communicate, interact with others, and have others see them as people. Students with Asperger's Syndrome are critiqued like Van Gogh's painting "Shoes of the Peasant" as discussed in *Heidegger: Basic Writings* (in Krell, 1977, pp. 141 & 158). The picture depicts a pair of brown shoes placed on the floor. When viewing the picture, the opinions of people run the gamut. Are they boots or shoes? Do they belong to men or women? Are they work or everyday wear? Does Van Gogh or someone else own them? Some people will just see a pair of worn leather footwear, while others will look beyond their surface. Just as this painting can trigger so many different opinions from any observer, so do people with Asperger's Syndrome. When a person with Asperger's Syndrome is observed, there seems to be a sense of surprise followed by hesitation. They do not know how to react. What do you see? What comes to mind?

Is it possible to look beyond the visual traits to see the person? What do they reveal about you? What hidden secrets resurface when one encounters a person with Asperger's Syndrome? It seems that people with Asperger's Syndrome are critiqued like artwork. The difference is the critic only observes the picture. The brush strokes, choice of colors, and thickness of the paint on the canvas are overlooked. Instead, a comparison is made about the style of the work. What does this resemble? Is it like a Monet? Is it abstract? What is wrong with accepting it as an original?

In the art of work such disclosedness is compellingly experienced perhaps most of all in the work of poetry. In poetry, we are less disposed to manipulate things or reduce them to our own technical-scientific, quantitative frames of reference; we are encouraged rather to let things be what they are and show their many sidedness. (Heidegger, in Krell, 1977, p. 344)

Heidegger's quote speaks to letting things show themselves for what they are, not changing them to what we want them to be. Works like poetry, music, art, film bring forth both originality and lived experiences. The following movie is about letting be, accepting persons as

they are.

*Punch-Drunk Love* is a movie about a socially impaired man. The character Barry Egan, played by Adam Sandler, was a successful businessperson who designed and manufactured plungers. He wears the same blue suit every day. Barry also has an anger management problem. His anger escalates when his sisters tease him. During his stormy times, he will destroy any property in his path. His only friends are his seven domineering sisters. They are constantly trying to find the perfect date for him.

Barry is looking for a woman to spend her life with him. When Barry meets and falls in love with Lena, played by Emily Watson, his life takes a turn. His first words of passion to Lena are “I want to smash your face in with a sledge hammer you’re so pretty.” Yikes! These words sound threatening. Most women would run for their lives after hearing them. Yet, these words did not alarm Lena at all. What makes Lena stay? She accepts Barry just the way he is. She appears to be a good match for him and a good social coach. Will Lena be able to keep up this role in the future?

You may encounter a person with Asperger’s Syndrome on any street, restaurant, grocery store, bus, job, theater, or other public place. Their idiosyncrasies may speak as loud as thunder or as soft as a whisper. Their neurological makeup cannot be separated from the person. They see the world with a different colored lens, a lens that makes sense to them. They have many sides that reveal who they are in many ways to different people. Sometimes, others consider the sides that are revealed unacceptable. At other times, depending on their station in life, their behavior may be acceptable. They are being themselves, while showing their many sides. Can we accept their human side?

### Moving On

In Chapter Two I investigated the lived experience of persons with Asperger’s Syndrome through a variety of sources in the literature. The experiences presented in this chapter speak to the struggles that these young people encountered as they meandered through the social maze of the community. I also shared the experiences of parents who were relentless in their attempt to assist their child through the social maze. Sometimes, the maze proved to be complicated, exasperating, and an endless journey for these young people and the families. Nonetheless, they continue to swim against the current to reach the circle of belonging. In Chapter Three, I discuss

the philosophical grounding, the philosophers that connect to the phenomenon, and the methodological design of the study, as I pursue my phenomenological question: **What is the lived experience of persons with Asperger's Syndrome?**

## CHAPTER THREE: PHILOSOPHICAL GROUNDING AND METHODOLOGY

In Chapter One, I shared with the readers what oriented me to the phenomenon of Asperger's Syndrome. I described the challenges that people with Asperger's Syndrome encounter when they attempt to socialize with others in their daily activities. I also described the challenges I face as a teacher working with students having Asperger's Syndrome. Observing students attempt to navigate the social mazes in school and the community set me on the journey to understand their experiences.

In Chapter Two, I explored a variety of sources and personal experiences from the literature that parents shared about their child. People who live with Asperger's Syndrome also shared what it is like to navigate the social maze of daily life. In Chapter Three, I describe the philosophic grounding, the philosophers that provide a foundation and connect to this study on the phenomenon Asperger's Syndrome, and the design and methodology of the study.

I chose phenomenology as the methodology for my study on the lived experience of persons with Asperger's Syndrome. Phenomenology permitted me to reveal the real faces of people with Asperger's Syndrome as I journey with them through their daily experiences. Van Manen (2003) has written, "Phenomenology is the systematic attempt to uncover and describe the structure, the internal meaning structures, of lived experience" (p. 10). It is not my desire to question why people with Asperger's behave a certain way. I want to gain a better understanding of Asperger's Syndrome and the experiences of those who live with the disorder.

In the field of education, teachers commit to developing students into independent and productive citizens. The twelve years of school are supposed to prepare students to transition from childhood to adulthood. Teachers are excited when former students return to school to share successful experiences. The news of their success circulates throughout the school, not only to those who knew the student, but to all teachers; as a team, everyone shares in the success. Unfortunately, some students return for additional support from teachers due to unsuccessful experiences. These experiences circulate as well. Successful and unsuccessful experiences often aid teachers in preparing the next group of students.

Van Manen (2003) writes, "We can only understand something or someone for whom we care" (p. 6). Understanding in this sense means it is important for teachers to learn and

understand as much as possible about students to be able to assist them in reaching their full potential. Students with Asperger's Syndrome often encounter hurdles throughout their school years. Often, those hurdles intensify in adulthood.

### Philosophical Grounding: Hermeneutic Phenomenology

This study is grounded in hermeneutic phenomenology. Hermeneutic phenomenology is a human science that studies persons (van Manen, 2003). What does it mean to study people? Why should one study people like art? Does one study the whole person or just the characteristics that are displayed in certain settings? Does one sit in an inconspicuous space to watch every activity a person may be engaged in at any given time? Van Manen (2003) states, "It means that the human being is being seen and studied as a 'person,' in the full sense of that word, a person who is a flesh and blood sense-maker. The human being is a person who signifies—gives and derives meaning to and from the 'things' of the world" (p. 14). What are these things of the world? Are they the same for everyone?

Hermeneutic phenomenology provides me an opportunity to show experiences of people with Asperger's Syndrome and the contributions they make in the community. Van Manen (2003) defines hermeneutics as "the theory and practice of interpretation" (p. 179). Gadamer (1975/2003) writes, "The classical discipline concerned with the art of understanding texts is hermeneutics" (p. 164). Understanding and interpreting a phenomenon allows for the bringing forth of something that is hidden out into the open. "Hermeneutics must start from the position that a person seeking to understand something has a bond to the subject matter that comes into language through the traditionary text and has, or acquires, a connection with the tradition from which the text speaks" (Gadamer, 1975/2003, p. 295). It is through the text that hermeneutic phenomenology allows me to study people with Asperger's Syndrome and understand the experiences they encountered as a family member, neighbor, co-worker, friend, and citizen.

Heidegger (1962) writes, "Thus the term 'phenomenology' expresses a maxim which can be formulated as 'To the things themselves!'" (p. 50). Heidegger (1962) goes on to note, "This expression has two components: 'phenomenon' and 'logos.' Both of these go back to terms from the Greek: φαινόμενα and λογος. Taken superficially, the term "phenomenology" is formed like "theology," "biology," "sociology" –names which may be translated as "science of God," "science of life," "science of society" (p. 50). *The Oxford Concise Dictionary of Etymology*

(1996) defines phenomenon, as meaning “show, be seen, and appear” (p. 349). *The Oxford Concise Dictionary of Etymology* (1996) defines logos as “gather, choose, recount, and say” (p. 270). When I read Heidegger’s quote, “to the things themselves,” I think about what some people fail to recognize when interacting with people with Asperger’s Syndrome. What is not recognized is the person first; they only see the behavior or concentrate on the disability. It is my goal to bring the person to the front as he or she interacts and lives in the world with others.

Van Manen (2003) notes, “The real understanding of phenomenology occurs by actively doing it” (p. 9). It is through the rich language in the text that I am able to bring to light the experiences of people who live with Asperger’s Syndrome. The language allows me to bring out the experiences through the voices of those who live with the syndrome. The language also will give those who may have had little knowledge about Asperger’s Syndrome a different viewpoint of the person. It is my hope to help people gain an understanding of the syndrome itself.

Safranski (1998) writes, “Phenomenological attention to the world of conscious processes requires an attitude that conflicts with the demands and complications of everyday life, because we pay attention to objects, people, and ourselves, rather than to how all these are ‘presented’ in our consciousness” (p. 81).

I think about Safranski’s mention of conflict. Conflict appears to occur for people with Asperger’s Syndrome when they attempt to meet the demands of daily life. As an educator, I feel the conflict as I transition students with Asperger’s Syndrome to adulthood. It takes so much planning to prepare these students for postsecondary opportunities. Sometimes, it means hand picking employers, as well as the environment, to make sure that the student is successful and the employer is satisfied. Sometimes, the placement is successful, and other times it is not. When that occurs, you start again from the beginning. It can be very stressful when a placement does not work out, especially since it is illegal to disclose a student’s disability. Nonetheless, I continue to concentrate on the student’s ability, while I assist them to self-advocate and problem-solve in a variety of settings.

The community is a vital part of our everyday existence. It is where we live, play, and work. Community usually fosters a sense of togetherness and keeps us grounded. Usually, when a person is new to a community or a job, co-workers and neighbors welcome him or her. One or more people may stop by to welcome the newcomer by introducing themselves and share

information about the new environment. However, some persons with Asperger's Syndrome may not get a visit from the welcoming committee. Heidegger (1971) writes, "Each being we encounter and which encounters us keeps to this curious opposition of presence in that it always withholds itself at the same time in a concealedness" (p. 52). What is present in an encounter with a person with Asperger's Syndrome is oddness. Although everyone possesses an oddness, which makes persons individuals, they are not socially dismissed. Challenges with socialization and communication conceal who people with Asperger's are as persons. My intent is to reveal people with Asperger's Syndrome as family members, co-workers, friends, or significant others.

Place is crucial to our existence. Casey's concept of place connects well with the phenomenon of Asperger's Syndrome. Casey (1993) notes, "Place is always on the agenda at the first level of human experience" (p. 110). Finding one's place in society is important. Place says a great deal about who we are as people. Place plays a major role in our past, present, and future. Place also gives us identity and provides a grounding when we feel out of place.

The question of place is especially of interest as I investigate people with Asperger's Syndrome. What is place? Does place mean something different for each person? What does it mean to be in-place? What makes one person feel in-place and others feel out-of-place? It is important to answer these questions since people with Asperger's Syndrome often have difficulty finding their place in society. Casey (1993) believes, "The true ecstasy of human experience is placial" (p. 111). He also writes, "In becoming implaced, we emerge into a larger world of burgeoning experience, not only by ourselves but with others" (Casey, 1993, p. 111). The difference found in people with Asperger's is that social experiences dwindle.

When I think about the word place, family, friends, and social gatherings come to mind. *The Oxford Concise Dictionary of English Etymology* (1996) defines place, which comes from the Latin word *platea*, as "space where people dwell" (p. 355). We dwell in many places with others. Place is everywhere we turn. Yet, people with Asperger's Syndrome have difficulty locating a place to dwell. They often search for a place like nomads in the desert, moving from one space to another in search of a home. They continue to search for their place within the vast wilderness of society.

## Do You Read Me!

Opening one's self to another in conversation can bring about an understanding of the other person's experiences in life, knowledge, beliefs and talents. Sometimes, conversations can be a springboard for friendships, or even, a love connection. During a conversation, a person may study the other to determine who they are as a person.

Conversation is a process of coming to an understanding. Thus, it belongs to every true conversation that each person opens himself to the other, truly accepts his point of view as valid and transposes himself into the other to such an extent that he understands not the particular individual but what he says. What is to be grasped is the substantive rightness of his opinion, so that we can be at one with each other on the subject. Thus we do not relate the other's opinion to him but to our own opinions and views. (Gadamer, 1975/2003, p. 385)

Gadamer's quote about conversation is significant for the study. We engage in conversations daily. The conversations can range from small talk to debates. Conversations also can range from pleasant to intense depending on the topic of discussion. Gadamer suggests that the one tie that keeps the conversation going is an understanding of opinions. Gadamer (1975/2003) notes, "We say that we 'conduct' a conversation, but the more genuine a conversation is, the less its conduct lies within the will of either partner. Thus, a genuine conversation is never the one that we wanted to conduct. Rather, it is generally more correct to say that we fall into conversation, or even that we become involved in it" (p. 383). Some people with Asperger's Syndrome may be one-sided in a conversation as they speak about a topic of their interest, not realizing that the listener has tuned them out.

Gadamer (1975/2003) writes, "...and if a person fails to hear what the other person is saying, he will not be able to fit what he has misunderstood into the range of his own various expectations of meaning" (p. 269). So often, others do not thoroughly hear the words of persons with Asperger's Syndrome. The bits and pieces that do filter through are often misunderstood, thus creating a barrier. These misunderstandings are like a barbed wire fence. The fence functions as a barrier, keeping people with Asperger's on one side and those they desire to interact with on the other side, making crossing the fence a risky decision.

Frith (1989) notes, “The consensus is that social ineptness in autistic individuals is most strikingly demonstrated in two-way interactions” (p. 136). Hearing what a person says is important in communication. Body language is just as important as the spoken language. Shock, surprise, sadness, anger, and worry generally show in a person’s body and facial expression. However, it is a missing link that keeps people with Asperger’s from being close to others. Did you hear me? Do you read me?

*Let Me Explain!*

Social gatherings can be a magnet for all types of conversations. Often, conversations do lead to debate and, at times, an argument may ensue without an offer of apology. Sometimes, people are able to see eye-to-eye, and other times they agree to disagree. The main objective is getting one’s point across by any means necessary. Imagine a person who feels it is necessary to explain him or herself before engaging in conversations. One person with Asperger’s shares the following about conversations:

I tell people, if you lose interest, stop me, because I won’t know it. The chemical neurotransmitter that would give me that message either isn’t there or doesn’t work.  
(Meyers, as cited in Leichman, 2003, p. F01)

Whereas this individual alerts you to the communication problem before engaging in a conversation, others with Asperger’s Syndrome may continue to talk without any explanation or agreement from the other person.

Frith (1989) writes, “It is pervasively documented that autistic individuals cannot easily understand language that is flippant or witty, and that instead they are excessively literal” (p. 134). When someone tells a joke or uses an idiom, people with Asperger’s Syndrome may not comprehend and ask for clarification. Happe (1991) notes, “It is a common observation that autistic people seem to miss what we would regard as salient in a situation, and pay close attention to what seems to us irrelevant” (p. 227). For example, during a conversation, a person with Asperger’s makes a comment on another person’s colors, clothing, or some object in the room. Since the speaker has difficulty reading body language, he or she may not realize that the listener thinks the comment is irrelevant to the topic at hand.

## *Understanding this Thingness*

Heidegger (1971) connects to the phenomenon with his interpretation of the “thingness of things.” For people with Asperger’s Syndrome, “thingness” reflects in the way they navigate through the world. Their way of experiencing the world is not acceptable according to the normal scheme of appropriate behaviors and usually causes conflict. Words like weird, freak, eccentric, dork, and geek often are used to describe persons with Asperger’s. People with Asperger’s Syndrome usually have difficulty with change. Yet, it appears that some people who interact with them also demonstrate inflexibility to change.

Perception is a powerful thing. It helps us to read a situation in times of danger and in social gatherings. Do you get to know this stranger or walk away? Often, people choose the latter when they encounter people with Asperger’s Syndrome. Heidegger (1971) writes, “What about nearness? How can we come to know its nature? Nearness, it seems, cannot be encountered directly. We succeed in reaching it rather by attending to what is near” (p. 164). What is near is a person who tries to fit into the environment, a person who is just like other faces in the crowd. Heidegger (1971) notes, “The High German word *thing* means a gathering, and specifically a gathering to deliberate on a matter under discussion, a contested matter” (p. 172). Yet, when people with Asperger’s gather among others to engage in discussion, the thingness often reveals itself. The passion they express for a particular subject usually gives some people the impression of a bragger. At that point, what was near creates distance between the person with Asperger’s and the people he or she encounters in face-to-face gatherings. These gatherings often push them further away from the nearness he or she desires which is to be with others.

Heidegger (1971) writes, “Only what conjoins itself out of the world becomes a thing” (p. 180). I am not saying that persons with Asperger’s are a thing or an object. They are human beings who contribute to society. However, the thingness that I speak of is the unprompted demeanor that places distance between them and persons that they desire to be near. This thingness keeps persons with Asperger’s in the shadows of others. Why does this thing (behavior) make others so uncomfortable? Things surely have a place and use in the world. What do things reveal? What do things reveal about truth? I examine this thingness of Asperger’s Syndrome.

### *Co-Dependency*

Parents prepare their children to be independent through modeling and support during the development years. The payoff is usually independence for the children and empty nest for the parents. Sometimes, life does not go as planned and the adult child may not leave his childhood home. Others may in fact leave home only to return at some point as an adult.

The most ancient of all societies, and the only one that is natural, is the family: and even so the children remain attached to the father only so long as they need him for their preservation. As soon as this need ceases, the natural bond is dissolved. The children, released from the obedience they owed to the father, and the father, released from the care he owed his children, return equally to independence. If they remain united, they continue so no longer naturally, but voluntarily; and the family itself is then maintained only by convention. (Rousseau, 1913/1973, p. 182)

Rousseau's words make perfect sense when you think about the natural order of the family. Traditionally, independence begins when individuals make the transition from youth to adulthood. Although cultures differ, the norm in the United States is that a youth/young adult usually leaves home at the age of 18. Usually, young adults often voluntarily move on with their lives and parents move on, too. They prepare for a new phase of their life called empty nest. Today, some adult children continue to live at home with their parents long after their transition from high school.

Baby bird is encouraged to fly high! What does a parent do when baby bird decides to fly back to the nest? Young adults may transition into the military, marriage, vocational trades, or employment. Nonetheless, they usually move on to a new life where they are able to make their own decisions and live as they please. Yet, for some adults with Asperger's Syndrome, voluntary independence may not be a successful experience.

### *Barriers to Independence*

Gaps in employment histories, poor communication, and socialization deficits often lead individuals with Asperger's Syndrome to some dependency on family members in adulthood. Issues such as safety, social life, and overall well-being become the responsibility of another adult. Frith (1989) writes, "They may remain at home as helpful companions to aging parents

who understand them” (p. 15). However, what is most unfortunate is a person with Asperger’s Syndrome living on his own with no support. What is it like for adults to have their lives supervised by another adult? How can a person receive support and maintain independence?

### *Transitioning in the Field of Special Education*

During my 22 years in the field of special education, I have worked with a myriad of secondary students with disabilities. In the last five years, I have worked with students who have significant social challenges who are able to compete successfully with academic requirements, but make failing grades when interacting with their peers; students who walk in the shadows of their peers, hoping to be recognized as a peer or a friend. Often, these students are judged as being unacceptable by the normal standard, leaving impressions that tend to stick like glue. Any talents or good deeds may go unnoticed, and the possibility of a relationship becomes unlikely. What is going on? Why is this happening to these young adults?

One of my encounters discussed earlier, involved a student entering my office while I was meeting with another student’s parents. Mark’s entrance caught everyone off guard and for a moment, I did not know what to say or do, as well as being upset by his intrusion. My first thoughts were that Mark was being rude and trying to get a rise out of me because there were visitors in my office. Surely, he saw five people sitting at the table. It amazed the parents as well that he did not speak or acknowledge their presence. His attention was fixed only on me, as if suddenly everyone else in the room had become invisible. He began asking me questions as if we were the only ones in the room. He was on a serious mission!

My encounter with Mark was so puzzling that I had to know more about him. I wanted to make meaning out of this experience. This led to the question, **What is the lived experience of persons with Asperger’s Syndrome?**

### Methodological Framework

This study focuses on members of society who navigate their world in ways that make them comfortable. They often pay the price of alienation for their unique way of navigating their world. Experiences shared in this study offer knowledge about challenges faced by people with Asperger’s. Yet, each person with Asperger’s Syndrome is unique in personality just like everyone else. When does missing the punch line of a joke or refraining from eye contact justify

alienation? My interest in persons with social challenges may seem a futile effort to some, but my experience as a witness of both the experiences of persons with Asperger's Syndrome and the reaction of those they encounter compel me to share their side. No one should be made to feel invisible. This study will show the person behind the syndrome and verbalize his or her experiences and contributions to society. Most importantly, this study will provide insight to those who enter the lives of adults with Asperger's Syndrome.

As previously mentioned the six research activities developed by van Manen (2003) will serve as the framework for phenomenological research to guide my study through the phenomenon of Asperger's Syndrome:

1. turning to a phenomenon which seriously interests us and commits us to the world;
2. investigating the experience as we live it rather than as we conceptualize it;
3. reflecting on the essential themes which characterize the phenomenon;
4. describing the phenomenon through the art of writing and rewriting;
5. maintaining a strong and oriented pedagogical relation to the phenomenon;
6. balancing the research context by considering parts and whole. (van Manen, 2003, pp. 30-31)

### *Turning to the Phenomenon*

This process involves turning to a phenomenon that seriously interests and commits us to the world. This activity involves orienting oneself to the phenomenon, formulating a phenomenological question, and explicating one's own assumptions and pre-understandings.

The starting point of phenomenological research is largely a matter of identifying what it is that deeply interests you or me and of identifying this interest as a true phenomenon, i.e., as some experience that human beings live through. (van Manen, 2003, p. 40)

My experiences as a teacher have oriented and shaped my turning to the phenomenon. Transition experiences of students with Asperger's Syndrome have captured my attention in such a way that I have become preoccupied with the way they navigate their world. Little things that we overlook in our daily travel like smells, temperatures, and touch often distract a person with Asperger's Syndrome, creating conflict. Shore, mentioned in Chapter Two, was sensitive to temperature changes in the work environment. Grandin, mentioned in Chapter One, was

sensitive to touch. When people look at a person with Asperger's Syndrome from the outside, they may perceive him or her as a complainer. People around them may want to scream out, "Deal with it and move on." Honestly, if it were that easy, I would not feel the need to bring their challenges to public attention. Their inability to communicate and socialize in an acceptable way with others in our socially dependent society has moved me to want to know more and has sealed my commitment to this population. I am oriented to this phenomenon as a person, citizen, and educator. I want to gain a better understanding of what the experience is like for people with Asperger's Syndrome.

As stated earlier, knowing too much about a phenomenon can keep us from getting to the truth and understanding of the phenomenon because we take too much for granted. In order to reach a deep understanding of the phenomenon, I must maintain a focus on the question at hand and put aside my own assumptions and pre-understandings. Although I work with these students on a daily basis, I must show the experiences without bias. Yes it bothers me when I witness others mistreat or judge students based on behavior. Of course, I think about students with the heart of a mother. The mother in me is constantly concerned about friendships and independence. We want our child to have a spot in the sandbox. Yet, as an educator, I have the responsibility of assisting young adults to transition independently into adulthood. They must prepare to meet the expectations of the adult world no matter how difficult the situation may be for them. For this reason, I must be open to their experience in order to help students realize their life goals and advocate for themselves in society. In order to help others gain a better understanding about Asperger's Syndrome I must face my preunderstandings so that I can gain an understanding of the phenomenon. In doing so, I must show people with Asperger's Syndrome as they attempt to navigate their world to provide the reader with a clear picture of the person being studied at all times.

### *Investigating Experience as We Live it Rather than Conceptualize It*

This process involves examining one's personal experience with the phenomenon as well as from others, tracing etymological sources, searching for descriptions of the lived-experience using a multitude of sources like conversations, experiential anecdotes, literature, biographies, diaries, journals, logs, art, and phenomenological literature.

After one orients oneself to the phenomenon, the search begins for a variety of lived-experience materials that reveal something about the phenomenon. In human science, this approach is called “gathering” and “collecting” (van Manen, 2003, p. 53). Van Manen (2003) says, “It is to the extent that my experiences could be our experiences that the phenomenologist wants to be reflectively aware of certain experiential meanings” (p. 57). Gathering and collecting lived-experience materials from a variety of sources can orient one closer to the phenomenon. These lived-experiences can in fact be experiences of any one of us. Van Manen (2003) cautions, “We need to realize, of course, that experiential accounts or lived-experience descriptions—whether caught in oral or in written discourse—are never identical to lived experience itself” (p. 54).

I shared my experiences in teaching in Chapter One. Like people with Asperger’s Syndrome, I was considered an outsider too. I did not receive a membership card from my colleagues. This was not a good feeling to be unwelcome. It was puzzling to me to be treated in an unkind manner, especially since we are constantly demanding that students treat one another with kindness and respect. Each attempt to fit in made me invisible. Soon, I became so transparent to my colleagues that I no longer saw my own reflection in the mirror. I made a choice to go where my reflection was visible.

I also described the roller coaster experiences of students and young adults who have Asperger’s Syndrome by engaging in close observation and verbal and written reflections as a way to enter their life world. The lived experiences shared by each person repeated the desire to be with others and the challenges they face to fit into the circle of friendship. I searched etymological sources for words and phrases that relate to Asperger’s Syndrome. These sources helped to describe what it is like to live with the syndrome and to put a face on those with Asperger’s Syndrome. Each source allows me to show the experiences in such a way that readers will see the possibility of having some of the same lived experiences as those shared in the study. This examination continued as I uncovered meanings of what it is like to live with Asperger’s with the participants in my study.

### *Text Gathering from the Participants*

Participants in the study met the following selection criteria: (a) between the ages of 18-50, and (b) diagnosed with Asperger’s Syndrome, Autism Spectrum Disorder, or High-

Functioning Autism as a primary disability. I solicited organizations that serve persons with Asperger's Syndrome for participants. From the list of names provided I called potential volunteer participants and shared the purpose of the study. Those agreeing to participate received a formal letter of invitation (see Appendix A) which explained the study and what they were committing to.

I had three conversations with four male adults and one female adult with Asperger's Syndrome. Their ages ranged from 28 to 53. Selecting adults who are 50 years of age may offer a balance to someone younger, revealing new insights for understanding this population as they transition from school through adulthood. Adults in their 50s may offer insight into what their experiences were like before laws were mandated to provide a free and appropriate education to children with disabilities. At the first meeting, the purpose of my study was explained to the participants. I shared my background in transitional special education to provide a rationale for the study. I also informed them that they are a valuable resource. I met with each person three times at a setting that was comfortable for conversation. The conversations lasted between 10 minutes to more than one hour each, over a three-month period. I asked participants to share an experience as a way to develop a relationship before the questioning. I asked open-ended questions like the following to initiate the conversation:

- Share a memorable social experience you can recall.
- What was your school experience like?
- Can you give examples of other experiences?
- What has it been like for you to transition from secondary school to adulthood?
- What are your experiences like at work?
- How have you experienced support systems?

These questions set the tone for conversations about the lived experiences of adults with Asperger's Syndrome. I asked participants to share a play experience from their youth and a work experience that stood out. After each conversation, I reviewed and transcribed the experiences, and looked for themes in the written reflections, the conversations, and interactions with the participants. Every experience a person has is unique and provides meaning. As I conversed and was in the presence of adults with Asperger's, I determined what tied the

experiences together. The thematizing process is further explained in a later section of the chapter.

The experiences participants shared assisted me in gaining a better understanding of students with Asperger's Syndrome as they transition from school to adulthood. When adults agreed to participate in the study, written expectations were provided, and they were asked to sign a written consent form (see Appendix B). Permission was obtained from the Institutional Review Board at Virginia Polytechnic Institute and State University (see Appendix D), assuring—among other things that questions would be answered before proceeding.

### *Hermeneutic Phenomenological Reflection*

This process involves reflecting on essential themes pertaining to the phenomenon by conducting thematic analysis, seeking meaning, uncovering thematic aspects, isolating thematic statements, composing linguistic transformations, gleaning descriptions from artistic sources, interpreting through conversation, collaborative analysis, and the use of what van Manen (2003) refers to as life world existentials as guides to reflection. Life world existentials include lived space, lived body, lived time, and lived human relation. Finally, I determined incidental and essential themes. Van Manen (2003) writes:

Phenomenological reflection on the lived experience is always recollective; it is reflection on experience that is already passed or lived through. (p. 10)

Phenomenological reflection is an attempt by the researcher to bring forward the lived experience of another as he or she has lived it, interpret its meaning as much as possible, and render it in a written narrative. The researcher searches for meaning of the phenomenon through the text gathered through conversation and writing. Gathering meaningful examples of the lived experience of adults with Asperger's Syndrome will assist in opening up the phenomenon to reveal itself.

Van Manen (2003) writes, "Meaning is multi-dimensional and multi-layered" (p. 78). It is important for the researcher to penetrate the many layers of the lived experience as a way to unfold themes. When the researcher listens with all the senses, themes surface from the lived experience through oral and written descriptions, and other sources used to show the

phenomenon. Unfolding the layers transitions the lived experiences of persons with Asperger's Syndrome from a state of silence to that of voice through the text.

Making something of the text or of a lived experience by interpreting its meaning is more accurately a process of insightful invention, discovery or disclosure—grasping and formulating a thematic understanding is not a rule-bound process but a free act of “seeing” meaning. (van Manen, 2003, p. 79)

I exercised a free act of seeing meaning not only with my auditory and visual senses, but with all of my senses as a way to allow themes to emerge. Reflecting on the conversations, gestures, written texts, and other gathered sources helped me to gain a full understanding of the lived experiences. This free act of seeing allowed me the flexibility of an artist who creates an image on a blank canvas, bringing the rich essence of the lived experience to full color.

Van Manen (2003) notes, “Desire refers to a certain attentiveness and a deep interest in an aspect of life” (p. 79). I have a deep interest in the lives of persons with Asperger's Syndrome, and it was and is my desire to make sense of their lived experiences. This interest compelled me to remain attentive in bringing forth their voices for all to hear. It was my desire to break the silence that so often makes persons with Asperger's Syndrome outsiders within the community. It was also my desire to bring the absent bodies that were once hidden in the wardrobes and closets of life into full view of society.

My awareness of my body is a profoundly social thing, arising out of the corporeality of other people and of their gaze directed back upon me. (Leder, 1990, p. 92)

Leder's quote speaks to the awareness a person has regarding another's perception of him. Another person's gaze upon us can say so many things when we are in the public eye. A gaze may make some people wonder if something is wrong with one's appearance. Often, this gaze makes a person take a second look at oneself. However, for persons with Asperger's Syndrome, a gaze from another is just a gaze. The shared experiences of persons with Asperger's will shed light on what another's gaze means to them. Van Manen (2003) notes, “... We try to unearth something ‘telling’, something ‘meaningful’, something ‘thematic’ in the various experiential accounts—we work at mining meaning from them” (p. 86). Extracting meaning from lived experiences captures possible essences of the phenomenon being studied. I looked for

themes to emerge as they related to the phenomenon. During the conversations, I paid close attention to body language, words, and the silence. After the conversation, I reflected upon what stood out in both the conversations and the written experiences. Uncovering themes assisted me in making sense of the phenomenon.

The key to seeking meaning is isolating thematic statements. What did I do with all the descriptions I gathered? What do they say about the phenomenon? Do they capture the meaning of the phenomenon? Van Manen suggests three approaches for isolating thematic statements:

- 1) In the wholistic reading approach we attend to the text as a whole and ask, What sententious phrase may capture the fundamental meaning or main significance of the text as a whole? We then try to express that meaning by formulating such a phrase.
- 2) In the selective reading approach we listen to or read a text several times and ask, What statement(s) or phrase(s) seem particularly essential or revealing about the phenomenon or experience being described? These statements we then circle, underline, or highlight.
- 3) In the detailed reading approach we look at every single sentence or sentence cluster and ask, What does this sentence or sentence cluster reveal about the phenomenon or experience being described? (van Manen, 2003, p. 93)

These approaches provided me with a means to capture themes as they emerged through gathered sources. The approach is dependent upon the researcher who may attend to entire texts, selected phrases and statements, or each sentence in order to seek meaning.

In determining the universal or essential quality of a theme our concern is to discover aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is. (van Manen, 2003, p. 107)

Van Manen examines universal and essential themes as they relate to the phenomenon. The researcher needs to ask questions about the significance of the themes to the phenomenon, which is what I did. What does this mean? When I think about the lived experience of persons with Asperger's Syndrome, it was important to reflect on the themes to make sure that what jumped out at me was inseparable from the phenomenon. I stayed focused on qualities that make Asperger's Syndrome what it is and why I am drawn to the phenomenon.

### *Hermeneutic Phenomenological Writing*

The object of human science research is essentially a linguistic project: to make some aspect of our lived world, of our lived experience, reflectively understandable and intelligible. (van Manen, 2003, pp. 125-126)

The phenomenological method consists of the ability, or rather the art of being sensitive – to the subtle undertones of language, to the way language speaks when it allows the things themselves to speak. This means that an authentic speaker must be a true listener, able to attune to the deep tonalities of language that normally fall out of our accustomed range of hearing, able to listen to the way the things of the world speak to us. (van Manen, 2003, p. 111)

Engaging in conversations with adults who have Asperger's Syndrome provides an opportunity for understanding their experience differently. Prior school experiences served as a guide since I continue to transition students from school into adulthood. After the conversations, I reflected and looked for themes that revealed themselves, further developed in the writing process. I provided the participants a copy of the transcript to review, and upon their review, we met again to make sure I captured the experience correctly. I then, determined which themes were essential to the phenomenon of young adults with Asperger's Syndrome.

This process involved describing the phenomenon through writing. Heidegger (1971) writes, "Language speaks" (p. 188). As I moved through the writing process, I listened with a keen ear regarding what was being spoken as well as the silence that sometimes occurred during the conversations and in the text. I attempted to get beneath the words, pulses, and silence. Van Manen (2003) writes, "The methodology of phenomenology requires a dialectical going back and forth among these various levels of questioning. To be able to do justice to the fullness and ambiguity of the experience of the life world, writing may turn into a complex process of writing and rewriting (re-thinking, re-reflecting, re-cognizing)" (p. 131). This process requires that the researcher exercise patience and commitment for the many writings and rewritings until a narrative that describes the lived experience is developed. In order to gain a better understanding of Asperger's Syndrome, I maintained awareness not to view the back and forth movement of the writing process as a negative experience. Instead, I chose to welcome this movement as a way of

bringing forth the full essence of the experiences of people with Asperger's Syndrome and the way we live with them in the community.

*Maintaining a Strong and Oriented Pedagogical Relation to the Phenomenon*

It is important to stay close to the phenomenon and be mindful of our pedagogical orientation. Van Manen (2003) notes, "Whatever approach we seek to develop, it always needs to be understood as an answer to the question of how an educator stands in life, how an educator needs to think about children, how an educator observes, listens, and relates to children, how an educator practices a form of speaking and writing that is pedagogically contagious" (p. 151). As I work with students with Asperger's Syndrome, I constantly reflect on their current and future needs. I also reflect on ways to provide ongoing support to students in order for them to be successful in their career preference and in the community. Van Manen (2003) notes, "Pedagogical theory has to be theory of the unique, of the particular case" (p. 150). This requires guidance from each team member who interacts with students in both the school and the community. Together, we can provide best practices for students to help make a smooth transition. Best practices include providing vocational assessment, community work experience, leisure activities, and practice in self-advocacy in order for students to reach their full potential as independent adults. Each student is unique when it comes to his or her needs and support systems. Educators must be able to understand the unique experiences of students and be mindful not to sculpt all students alike.

Van Manen (2003) writes, "...As we speak or write (produce text), we need to see that the textuality of our text is also a demonstration of how we stand pedagogically in life" (p. 138). Educators have so many tasks and mounds of paperwork to complete during the school day that it is easy for some things to take a place on the back burner. As educators, we must look at our way of being in the world with children and adults. When educators observe learners in school or the community, we must reflect on those experiences to determine if they are being successful. We must always determine the best approach to support students to problem-solve in any challenge they experience even when we are not in their presence. Most importantly, we need to listen to what those experiences are saying about students and the type of accommodations needed in order to provide ongoing support.

Van Manen (2003) states, “Pedagogy is this questioning, this doubting. We wonder: Did I do the right thing?” (p. 147). Educators should keep this question in mind as they continue to live with students. This wondering will help educators maintain a focus on their purpose for being in the classroom and reflect on their commitment for educating students. I allowed the experiences of people with Asperger’s Syndrome to speak for themselves without allowing my passion for this group of people to stand in the way. Their voices resonate throughout the study.

#### *Balancing the Research Context by Considering Parts and Whole*

Each of the activities discussed above came together as a whole. Van Manen (2003) writes, “One needs to constantly measure the overall design of the study/text against the significance that the parts must play in the total textual structure” (p. 33). Therefore, it was important to balance the research context in order to remain oriented to the research question, **What is the lived experience of persons with Asperger’s Syndrome?** It was also important to be animated, attentive and open through each part of the process to reveal the essence of the phenomenon through the writing process. I kept mindful that I must reflect on each part of the study to make certain that I stayed on course, and that I must exercise tact and remain grounded at all levels of the study.

#### Looking Ahead

In Chapter Three, I have shared the philosophic grounding, framework, and the philosophers that connect to this study. In Chapter Four, I uncover the themes found in the lived experience accounts of person with Asperger’s Syndrome and interpret the meaning that lies therein for themes to make sense of what the text is communicating. In Chapter Five, I bring forth the pedagogical insights and make recommendations for how persons with Asperger’s might be helped to live more meaningful lives. It is my attempt to show their journey as our journey. It is my hope that this study will give others a better understanding of people with Asperger’s Syndrome, to view them with fresh eyes. I hope that those fresh eyes will be able to look beyond the challenges and focus on the unique qualities that make each individual a contributing member of society.

CHAPTER FOUR:  
BEYOND THE PLACESCAPES OF HOME: ASPIES TRACE THEIR FOOTPRINTS IN THE  
LANDSCAPE OF PLACE

Any stability we experience is precarious. Even though we know where we are in relation to other places, we lack a sure sense of where our own place is. What we lack, therefore, is twofold: *stabilitas loci* (“stability of place”) and inhabitancy in place. (Casey, 1993, p. 109)

To find such stability and inhabitancy, it is not enough to disembark. On land we may gain stability underfoot, but we will still be exposed overhead. Unless we discover a hospitable cave or a very dense rainforest, we must take special action. When we cannot find a habitable place, we must set about making or building such a place to ensure stable inhabitation. (Casey, 1993, p. 109)

Casey writes about stability and inhabitancy. We live in this world together. Except for our private spaces, we share the roads we travel, the work environment, restaurants, grocery and department stores, entertainment venues, communities, and places of worship. These are superficial habitations. What people want is a place to call home. We may have a place to live, but we journey in inhospitable milieus, as Casey (1993) describes:

A landscape seems to exceed the usual parameter of place by continuing without apparent end; nothing continues it, while it contains everything, including discrete places, in its environing embrace. The body, on the other hand, seems to fall short of place, to be ‘on this side,’ the near edge of a given place. (p. 25)

Where is this given place? How does one surpass the edge? Many people with Asperger’s Syndrome live among us in the community. They are our neighbors, co-workers, and our loved ones. Yet, they are often outside the circles of friendship that many of us may enjoy and take for granted. Many individuals may lack kinship in the community, and long to find a hospitable and habitable place among “Neurotypicals,” a term coined by people with Asperger’s Syndrome when speaking about people who do not have the disorder. Neurotypicals live next door, across the street, or share the next cubical in the office. Everyone needs roots to feel connected to something larger than themselves, but some individuals with Asperger’s Syndrome seem to be

stunted as they attempt to find their place and relate to others around them. In this chapter you will hear their stories.

This study addresses the question: “**What is the lived experience of adults with Asperger Syndrome**”? To begin the journey through this phenomenon I share the lived experiences of Arthur, George, Robert, Shirley, and Walter (pseudonyms), the participants in my study, who are adults living with Asperger’s Syndrome. I invite you into their world and the world of people with Asperger’s Syndrome also known as “Aspies.” By the end of this chapter you will have heard about their transition from childhood to adulthood, life in the community, work environments, and relationships. Their stories reveal explicitly what it is like for these Aspies to live in a neurotypical society. Each person openly shares his or her unique experience about living in a “cookie cutter” society. They want to be a part of society and want others to see them as individuals, not as a label or a disability.

What does it mean to “be” in a neurotypical society? Society is made up of diverse communities that are rich in cultural backgrounds, where many languages are spoken. There are many occasions to celebrate with family, friends, and others we meet during our lifetime. Those of us who belong to the neurotypical society possess skills and abilities that afford us the opportunities to work in a variety of occupations, and live in communities of our choice. We exist in the presence of others. We live in neighborhoods with community centers that offer an array of leisure activities and personal development courses. There are block parties, local and national celebrations, as well as get-togethers at the homes of selected neighbors. Who gets these invitations? and Who comprises the guest list? Aspies tell their side of what it is like to live outside the neurotypical society.

### Meet the Participants in Their Places

To introduce my participants, I begin by sharing what it was like for them when they found out that they had Asperger’s Syndrome.

**Walter** is a 44 year-old male. He earned a bachelor’s degree in finance and he was diagnosed with Asperger’s Syndrome at the age of 36. He admits that socializing with others was always a challenge for him. Walter was also diagnosed with depression which went unrecognized for a period of time. The depression along with chronic anxiety made it more difficult for him to navigate daily life activities. Yet, he continued to go on with his daily routine.

After reading articles about Asperger's, and recognizing some of the symptoms, Walter decided to find answers to the many questions he had about Asperger's Syndrome. He began a search to know the truth, and most importantly, to be able to name what he had experienced in his life up to this point. Walter was able to identify "what" had challenged him for so long. He calls that moment a "grand ah-ha." He admits:

Having Asperger's, it's always been difficult to socialize. I've managed to hide my shyness sometimes. It's been more difficult in the workplace. My friends are usually idiosyncratic. Some of them may be a little eccentric, and I think in my case very intellectually stimulating. (Walter)

Walter is currently unemployed and on disability. He lives independently.

**Shirley** is a 46-year old female. She was diagnosed with High-Functioning Autism as a child. She recalls childhood beginnings.

Well, when I was 4 and a half years old I had brain fever. I was diagnosed with Autism. I was in special education classes until eighth grade. And then they put me in regular classes. (Shirley)

After eight years in special education, she was placed in general education classes. Although Shirley's responses to my questions are short, the experiences she shares are powerful. In our conversation, Shirley states that she found herself riding a roller coaster. Currently Shirley is working as a library assistant, and lives with a family member.

**Robert** describes feeling a release when he was able to name what was going on with him — Asperger's Syndrome.

My first feeling was a big release and a relief because it was – I'd always been -I'd always considered myself the type of person that if I'm presented with a problem, I figure out a solution. And fix whatever the problem is. And I'd come a long way in my life doing that. I taught myself how to program computers. I don't have that degree in it. So it's anything I've been presented with I try to find solutions for and overcome. But there was this cluster of things that I just couldn't fix. I couldn't figure out why. And I tried all the, read all the books, got advice, you know. And the hardest thing had to do with relationships with other people. It's just like there are certain – there was a certain level

of I guess superficiality I pretty much had to put up with, even though I had acquaintances, people that I would call friends. Though I wanted to think of someone to call and say, “Ok, I want to go to see so and so movie. You want to come with me?” I had no one to call. You know that’s the type of friendships I had as an adult. So I had my work related friends or related to certain civic groups or something of that sort. Just there’s nothing, no person that I could go to outside of those activities. (Robert)

According to *Webster’s Unabridged Dictionary of the English Language* (2001), release comes from the Latin word *relaxāre*, meaning, “to free from confinement” (p. 1627). Diagnosed with Asperger’s at the age of 44, Robert found ways to work through and overcome his problems. He knew how to seek resources to reach solutions. Yet, he was not able to understand why he had a hard time relating to others. He learned to live with something that was at the core of his being. After trying every solution he could think of to remedy the problem, Robert finally felt free when he realized that it was not something that he had caused. He put a name on what was happening to him. He was finally able to call it Asperger’s Syndrome.

**George** is a 54 year old male. He was diagnosed with Asperger’s Syndrome at the age of 53. He acknowledges that he has had difficulties maintaining personal relationships.

Okay. Well I’ve never been able to keep a relationship, personal or job. The longest job I’ve ever had has been a year and a half, and then I’ve had three marriages, and they’ve only lasted about a year each. (George)

George earned both a bachelor’s and master’s degree in Journalism and he is currently unemployed, but continues to search for meaningful employment. The traditional work environment has been both a challenging and isolating place for him. He has much to contribute to the workforce, but he is unable to maintain tenure. He lives independently with the support of family. Like Shirley, George’s interviews were short but very informative.

**Arthur** is a 28 year old male. He was diagnosed with Asperger’s Syndrome during his adolescent years, when the syndrome was still new in the United States.

I was diagnosed with a whole lot of stuff, not necessarily Asperger’s. It was back in the mid-90s. It wasn’t commonly diagnosed [then]. I just kind of shrugged it off. You know,

I was too young at the time to really comprehend a lot of what was going on, so it didn't – it didn't really mean a whole lot to me. (Arthur)

The teen years are a time when one searches for identity, friendships, and discovery of the world outside the home. Imagine hearing that you have a disorder that limits your social ability. This limitation places you outside the social scene that adolescents enjoy most, socializing. Arthur, being a teen, did not understand what the diagnosis meant. His teachers, family and others knew very little about Asperger's Syndrome as well, since it was just being introduced into the *Diagnostic and Statistical Manual of Mental Disorders* in the United States. Arthur is currently employed as a contractor in the area of Financial Management, and he lives independently.

Each participant describes his or her life in a way that provides insight on how they faced challenges that often go unnoticed to those of us in the “neurotypical society.” Their stories reveal the difficult journey through inhospitable milieus. Their journey continues with remembrances of school.

### Old School Days

Sometimes, children have been described as having a quiet mannerism because they may not initiate conversation or play with peers. You may find them reading a book in the cafeteria while their classmates are engaged in organized activities, socializing, or just sharing the latest gossip. To an observer, they may seem content. After all, they seem to be enjoying a great book. What really lies beneath their quietness?

Students leave each level of school (elementary, middle, and high school) with memories. For most students these memories evoke happy times as well as negative ones. Adults with Asperger's Syndrome recall their school experiences mostly in terms of negativity, years that were not filled with smiles and great memories. What makes their stories different? Based on my conversations with George, Arthur, Shirley, Robert, and Walter, they have experienced hurdles during their school years that most would find difficult to navigate.

### *Sticks and Stones*

Sticks and stones may break my bones but words will never hurt me. (*Cambridge International Online Dictionary of Idioms*)

These familiar words have often been used in response or in defense to someone who says hurtful things about or to a person. Children have used this line to deflect hurtful words aimed at them. For a child, these or similar words penetrate like a bee sting. It hurts!

Many children may have been the victim of a bully at sometime during their school years. They may experience name-calling or other forms of bullying from schoolmates. Children who have been targeted by bullies may ask, “Why me?” Asperger (1944/1991) notes, “Autistic children are often tormented and rejected by their classmates simply because they are different and stand out from the crowd. The conduct, manner of speech and, not least, often grotesque demeanour cries out to be ridiculed. Children in general have a good eye for this and show great accuracy in their mocking of conspicuous character peculiarities” (p. 79). Although everyone rejected in this manner does not have Asperger’s Syndrome.

School is an environment where children learn to be sociable. Opportunities from social interactions generally occur in the classroom, on the playground and other school related areas. Students often are graded on how well they interact with peers. What does it mean to be sociable? *The Oxford Concise Dictionary of English Etymology* (1996), defines sociable from the Latin word *sociabilis*, meaning, “unite” (p. 447). Yet, the social connection does not occur for Aspies; in fact, there is a social disconnection. Once again, the circle game is played. “I am in and you are out.” In this situation, school becomes a less positive climate for those students who are outside the circle. Reflection on school experiences brings out painful encounters in this place:

Well, it was very painful, but I was very unpopular. They would taunt me, and I would react by biting my fingers, or just act very nervous, and it hurt. It really did. (George)

Oh, it was terrible when I was young. I was ridiculed. I was laughed at all the time. I had very few friends. In fact, one of the reasons I’ve never had children was I didn’t want to put anybody in the world who would have to go through the same ridicule as I did. (George)

The word hurt stands out in George’s description of his feelings. According to the *Webster’s Unabridged Dictionary of the English Language* (2001), hurt comes from the Middle English word *hurten*, meaning “to cause mental pain or offense, as an insult” (p. 935).

Smokowski and Kopasz (2005) write, “Lacking sufficient self-esteem and assertiveness to stand up for themselves, victims are usually not willing to report the bullying. This unwillingness to disclose their victimization may act as a signal for bullies and may cause these victims to be targeted repeatedly” (p. 104). George talks about having been bullied often by classmates during his youth. Colvin (2006) asserts, “Bullying not only hurts a child’s feelings, but most often the words or actions carried out by the bully make such a lasting impression on the individual that they carry the burden with them for the rest of their lives” (p. 48). For George, being the victim of bullying penetrated so deeply that it had an impact on his family planning, perhaps out of fear that history would repeat itself.

What is it like to encounter hurtful words and acts daily and still try to concentrate on math, reading, and arithmetic? MacDonald and Leary (2005) write, “We propose that social pain hurts because social inclusion was and is key for human survival” (p. 205). Being in a relationship with others gives us presence in the world. George was excluded from the social circle that his classmates enjoyed.

As we talk, I observe the pain in his face as he shares his school experiences, being cautious with his words. I remind him that he does not have to share the experiences if it is too difficult for him. After sharing his experiences, he becomes quiet. Even at age 54 George still feels the pain of childhood bullying; yet, he still desires a relationship with others, as does Shirley who talks about the pain of exclusion and torment.

Well, I get my feeling hurt, and I get kicked out. I get slapped. I get beat up, and they...and especially boys in school when I was young. And then, I said, “Leave me alone,” and they didn’t leave me alone, so I called the principal. (Shirley)

Shirley describes getting her feelings hurt many times during her school years. She was often the victim of verbal and sometimes physical abuse. Smokowski and Kopasz (2005) articulate, “Verbal bullies, on the other hand, use words to hurt or humiliate their victims. Bullying by this type of bully happens rapidly, making it difficult to detect and intervene” (p. 102). This seems to be the case for Shirley who had to seek assistance of an authority figure. And according to Shirley, many times these authority figures did not intervene on her behalf.

Being the new kid on the block can be difficult for many young people. However, there is usually one friendly person who steps forward to make the new person feel welcome. When

Shirley transitioned to general education, she did not feel welcome by her classmates. In fact, she says that she felt uncomfortable in this new environment. Shirley just wanted to fit in with her classmates. Instead, she became a target for her classmates. These kinds of school memories usually get locked in a person's private drawers and closets out of sight. However, school experiences were still fresh in Shirley's mind. They are not memories that she wants to share freely with others. School was a lonely place for Shirley.

Robert states that he wanted the same thing as other children, a friend. Instead, he had to deal with name-calling and physical abuse from his classmates.

Elementary school. I was picked on. I was punched. I was called a retard. I was ostracized. It was a painful experience.

But I remember one time this kid named Earl, you know cause I didn't have friends. I always wanted to have friends. And Earl came by and just you know responded. He was laughing. And said, "Hey, just meet me after school and I'll beat you up." And I thought, "Wow, he's just kidding. He wants to be friends." So I showed up. And he beat the snot out of me and I was like stunned. I walked home like, "What happened? I thought he wanted to be friends." But I just didn't clue in that you know he was serious. But I have no idea how long it would have gone if you know it hadn't been broken up by teachers. We were both, Earl and me, hauled to the principal's office. You know. But that happened to me all the time. I was just picked on, picked on, picked on. It just didn't stop. Absolutely didn't stop. (Robert)

Craig and Pepler (2007) write, "Being safe in relationships is a fundamental human right. Every child and youth has the right to be safe and free from involvement in bullying" (p. 87). Being the target of a bully can change a child's perception about school. Haddow (2006) notes, "The bullied students' perceptions of the school environment were also significantly different from their non-bullied peers" (p. 43). For Robert, the bullying did not stop him from searching for a friend.

Robert's early school experience bears resemblance to both George and Shirley's. Robert mentions that he stuttered when he was a child and received speech services. He did not indicate that he was teased when he stuttered. However, children seem to be good at targeting differences in a person. They can be cruel, especially when they know they can hurt another child. San

Antonio and Salzfass (2007) note, “The prospect of being friendless or getting teased looms large for many students at this age and can profoundly affect their sense of affiliation with school” (p. 32). Robert may have mistaken Earl’s laugh as a friendly gesture. He thought Earl would make friendship a reality for him. Since he had never had a friend, Robert lacked the social awareness to read Earl’s real motive. He assumed a laugh to be a positive characteristic of friendliness. Yet, Robert’s experience with Earl was all but friendly. He learned that there are many motives behind a laugh. Robert knows what it is like to deal with bullying daily. Like Robert, Arthur experienced bullying daily and he shares what it is like to be a bully magnet.

Spending a lot of time in the principal’s office. Usually fighting. I notice on some pieces of literature people will link aggression as being Autistic/Asperger symptom, but that’s not really accurate. The thing is when you’re Asperger’s you’re a bully magnet. (Arthur)

I try to avoid fights when I can. I don’t cause trouble. The thing is when there is always someone who wants to pick on you, you really don’t have a choice. Teachers give all these really bone-headed pieces of advice like, “Just walk away.” If you just walk away they follow you. The “Oh tell them you don’t like it.” Yeah, letting them know that it bugs you is the surest sign of – way to encourage them to keep doing it. Well, teachers don’t like to react to things that they can’t verify, and no one will ever do anything in front of a teacher. They wait ‘til the teacher’s back is turned. And if you get a reputation for being a tattle-tale, then you lose whatever standing you have. (Arthur)

San Antonio and Salzfass (2007) explain, “Bullying most often focuses on qualities that students (and the broader society) perceive to be different from the established norm, such as expected gender-specific behavior for boys and girls, dress and physical appearance, and manner of speaking” (p. 32). Arthur reached out to his teachers, but since the teachers did not observe the bullying, little was done to stop it. Arthur grows tired of the bullying and takes matters into his own hands. It must have been difficult for Arthur to be on the defensive each time a peer approached him on the school grounds. How much does a person have to take before he or she reaches a breaking point? According to the *Webster’s Unabridged Dictionary of the English Language* (2001), defensive comes from the *Latin* word *defendere*, meaning, “made or carried on for the purpose of resisting attack” (p. 522). Arthur tried following the rules. However, the bullying reached a point where he just dealt with the consequences that followed. Arthur refused

to be a bully magnet. Sitting in the principal's office was a small price to pay for standing up for himself.

Haddow (2006) asserts, "Bullying is a real experience for those who have experienced it. The outcomes of being bullied far outlast the initial event. The residual effects of being bullied are quantifiable and impact physical health, emotional health, school performance, involvement in altercations and perceptions of the school environment" (p. 50).

Arthur, George, Shirley, Robert and Walter became "bully magnets." What makes a bully magnet so different from their peers? Omizo, Omizo, Baxa, and Miyose (2006) claim, "They are more anxious and insecure. Victims are also physically weaker and appear to be lonely in school. They seem to send out a message to other students that they are insecure and worthless children who will not fight back" (p. 93). These characteristics seem to make children with Asperger's Syndrome a target for bullies. The magnets they became for taunting, propel them further and further from their goal of friendship.

Although schools have rules to protect students from harm, teachers and other staff can not see every incident that happens during the school day. The advice generally from teachers is to walk away, which may give a bully the impression that he or she is being ignored. This may give the bully more of a reason to continue the verbal or physical attack on a person. The playground, hallways, and any place that is out of the teacher's vision become opportunities for payback.

Being on the defensive is something that usually occurs in competitive sports, not in school. Arthur and Shirley were faced with the decision to tell and become subjected to ridicule later, to maintain silence, or just fight back and face the consequences. This kind of situation puts so much stress on the individual to worry about his or her safety, day after day. Arthur felt that he had no choice but to defend himself, while Shirley sought a higher power.

Walter's experience is different from Arthur, Robert, and Shirley. Bullying occurred in his early and middle school years.

I was teased in elementary school and up through about seventh grade. Starting in eighth grade through high school, I thrived, because I would hang out with people who shared my interests, student government, the school newspaper, the debating team. (Walter)

He did not share any experience in particular. Walter figured out early how to avoid the teasing from classmates. By participating in organizations with others who shared his interests, Walter was able to fit in and gain acceptance by his peers.

Many persons have experienced some degree of bullying during their school years. Each person handles his or her aggressor differently. Asperger (1944/1991) says, “It is possible for autistic children to earn respect, even if it’s mixed with ridicule, either through sheer intellectual prowess or through particularly ruthless aggression” (p. 79). Each participant remembers the experience as if it were yesterday. The experiences of being bullied by classmates started them on a journey to find a place where they could fit into the neurotypical society.

### *Finding a Fit among the Neurotypical Footprints in Society*

An important part of getting back into place is having a place to get back into. Since we don’t have any such place by mere fact of existing on earth, we must build places in which to reside. In creating built places, we transform not only the local landscape but ourselves as subject: body subjects become fabricating agents. (Casey, 1993, p. 111)

As I listen to the early school experiences of the participants, I drift back to follow my footprints during my early school years. In my mind, I scan the playgrounds, parks, and school environment to gain an understanding of why some of my classmates seemed to fit in and others did not. What was the secret? What helped me fit in with my peers and find place? I attended school with many family members, and my classmates became a part of my extended family members. Would my situation have been different if I did not have family members in the same school from elementary through high school? Some children may not have a single relative attending the same school. Yet, they find place along with their peers. Whereas, some children have difficulty finding place. Portway and Johnson (2003) add, “It is interesting to note that parents referred to their children as being ‘in school but not of school,’ in that they attended their local mainstream school but did not fit into the school system or with their peers” (p. 439). Often, children with Asperger’s Syndrome maintain an outsider status. They just do not fit in. I thought about this as I listened to the school experiences of the participants.

As I continue to reflect on my early school experience, I wonder what it must be like to miss the joys of childhood such as playing games, attending social events, or being with friends

and sharing stories. We all may have an experience or two from our childhood that we may not wish to share with others for one reason or another. Yet, many adults enjoy sharing memorable experiences about childhood friends or experiences (good or bad) that had an impact on their lives. These experiences may resurface during a celebration with family or friends. Many times, these memories impact the person who had the experience and those who witnessed it or were close to the person during the time that experience occurred. Those childhood experiences become the ties that bind lifelong friendships. These binding ties are lacking with my participants.

Portway and Johnson (2003) contend, “The usual pleasures of socializing, of friendships and close relationships seemed to be denied to them [Aspies], yet the desire to be like other people was intense. They saw their peers ‘joining in’ and seemingly enjoying the company of others, and many wanted to be able to join in too” (p. 439). Instead, they were members of the outsiders’ club. They play the role of a spectator rather than a participant. People with Asperger’s Syndrome often are stumped by social expectations. This makes them unsuccessful players in the social game. Sperry and Mesibov (2005) assert, “...Their lack of fluency in the foreign language of social interaction may hinder their efforts to initiate and sustain friendships” (p. 363). This lack of fluency in the social game hinders their chance to be with others to build memories.

Those early years were challenging for Arthur, Shirley, George, Robert, and Walter. Yet, these individuals persevered in their quest to find a place where others shared common interests. Where is that place? Who are the people on the other side of the circle? Everyone wants to have a place to call his or her own. That place is usually friendly, secure, and consistent. Casey (1993) notes that one must build such place. The participants share how they found their place during their school years, within the walls of higher learning, and during transition to adulthood. Each found a place where he or she could be like everyone else, visible and heard. Each found a place where his or her uniqueness was appreciated. Yet, to reach that place, they had to overcome their invisibility.

### Overcoming Invisibility

What is it like to live under a cloud of invisibility? No matter where Aspies go, there is a sense that although they are present, no one actually sees them. The brightest shade in the color

spectrum offers little optimism for visibility. They are a translucent figure among the crowd. People with Asperger's Syndrome are more likely to feel invisible than their peers. Aspies in this study share their experiences of invisibility.

### A Place of Invisibility

I am an invisible man. No, I am not a spook look those who haunted Edgar Allan Poe; nor am I one of your Hollywood-movie ectoplasms. I am a man of substance, of flesh and bone, fiber and liquids—and I might even be said to possess a mind. I am invisible, understand, simply because people refuse to see me. (Ellison, 1947, p. 3)

Ellison speaks to the invisibility that a person may experience in his or her daily life. According to my participants, people with Asperger's know too well the meaning of invisibility or not being seen by others. They are all too familiar with seeing doors closed to social and employment opportunities. They are no strangers to silence.

### *I am Here*

Van Manen and Levering (1996) assert, "The recognition of one's visibility is as consequential for the development of self as the recognition of the possibility of invisibility. Inner invisibility, or secrecy, is ultimately only possible after the fact of visibility" (p. 97). According to the *Webster's Unabridged Dictionary of the English Language* (2001), the word visibility comes from the Latin word *visibili(s)*, meaning, "the ability to give a relatively large range of unobstructed vision" (p. 2126). Arthur, Shirley, George, Robert, and Walter found visibility through their individual strengths. Arthur earned respect first by defending himself against the bullies and his acting talents. George and Walter used their writing skills to connect with others who shared the same interest. Robert used his acting and computer abilities, while Shirley used her musical talent. Their skills, abilities, and talents helped them fit into a social circle. They gained visibility among their classmates and extended it into the community. They had presence and their voices were heard as they found a way to minimize the harassment from classmates. They finally broke the silence that plagued them in the past.

George was the editor of his high school newspaper and worked for the campus paper while in college. He enjoyed being a part of the newspaper staff in high school and college. George admitted that college was a better fit for him. He found place in what he enjoyed,

writing. A newspaper environment can be a pressure cooker, with timelines and deadlines. Apparently, George was able to navigate that environment. Writing was his passion. According to the *Webster's Unabridged Dictionary of the English Language* (2001), passion comes from the late Latin word *passio*, meaning “a strong or extravagant fondness, enthusiasm, or desire for anything” (p. 1418). Writing is a natural talent for George. He used his writing skills to gain visibility.

An editor has an important role. He or she has the final say in what is printed and what is trashed. It is evident that George possessed the skills to hold the position of editor. Inside the newspaper office, he was an important person. Outside the “newsroom,” he became invisible again. Hurlbutt and Chalmers (2004) explore work experiences of adults with Asperger’s Syndrome. They acknowledge, “They expressed having difficulties with the social aspects of employment but not with the actual job duties” (p. 218). George was comfortable with his writing abilities, which seem to offer him a sense of accomplishment in the workplace. Hurlbutt and Chalmers (2004) also note, “Being successful at a job involves a great deal more than just doing tasks” (p. 218). Perhaps George immersed himself in his work in such a way that he may not have been aware of his social absence in the office.

Walter found his place with a few school sponsored organizations. He served on the student government, the school newspaper, and the debating team. Within these activities, he found others who shared his interests. He adds:

Every now and then, I would have lunch with some eccentric friends. One fellow was fluent, taught himself Welsh Gaelic, if you can image that. And the other fellow was a math impresario, very widely read in history. So it was very easy to find my niche in high school. (Walter)

Arthur found a place in high school. He participated in the theater program and ran cross-country for two years, but admits that he did not like it. He adds:

Try growing up being a boy without the stereotypical male interests, not caring about sports, not caring about cars. You know, even if you’re trying to interact you don’t have a common frame of reference to use, to interact with. And I did try watching a few games. Just I figure well if I know what’s going on, then whether I care about it or not, at least

I'll have something to interact with for balance, but less than five minutes later my mind comes wandering on to something else, and I just could not pay attention.

Arthur did not share the stereotypical interests of other males. What was it like for a male not to enjoy sports, which are considered typical male activities? This is a challenge that Arthur put distance between himself and his male peers. While other men were engaged in team sporting activities, Arthur chose to engage in one-on-one sporting activities that he enjoys. Where is it written that all men must like team sports? If a man does not like team sports, will his male counterparts view him differently? Our society places much importance on sports. We hear about a sporting event everywhere we go. People have loyalties to teams and proudly wear their favorite team jersey. Some become diehard fans and have sports parties to watch their teams play. They will challenge anyone who loves a rival team. Arthur was not interested in the typical team sports and he did not care who knew it. He is goal oriented and prefers individual sporting activities that allowed him to challenge himself.

At first, Arthur attempted to follow the game, but it was no use. He knew that a team sport was a way to connect with others. Sports provide a social outlet for many people. He decided not to pretend to enjoy team sports for the sake of a social outlet and not to allow team sports or any male oriented activities to validate who he was and chose to participate in sport activities that he enjoyed. Arthur is aware that interest in team sports activities is a big social connector and he respects that, but he wants others to respect his choice in individual sporting activities. To him, it is a matter of choice.

Robert, however, seemed to find place in high school activities. He is animated as he shares what his experience was like.

Being in both drama club and choir. I kind of had – also my sophomore year in high school was the first, actually virtually the only programming class I ever took was in my sophomore year in high school. Back then it was called computer math. And back then the PC hadn't been invented yet. So we were on this old rickety workstation. And I enjoyed the class so much my sophomore year that I took it again my junior and senior years for no credit. And my senior year, the teacher took me and some others in the class to a programming contest at Southern Methodist University. And I placed fifth. Which is

not all that big of a deal until I realized that my high school's valedictorian placed twelfth.

In the drama club, I felt I was actually part of a club. I felt accepted there. Choir. But I wasn't part of a club there. I mean I wasn't part of the inside group, the clique. It was still something that I enjoyed doing. Enjoyed the concerts of that sort. I thought I was really good at acting though. Particularly the strange characters. You know. So I got to play kind of the strangest characters. Did well at it. (Robert)

Robert found his place in computer math, on his high school stage, and as an active member of his church's youth group. Robert also found that performing with peers boosted his confidence and started him on a journey to continue developing his personal satisfactions. Beating out the smartest student in class earned him bragging rights. After high school, Robert enrolled in a community college where he earned an Associates degree in drafting.

Robert enjoyed the school choir, but drama appeared to be a sure hit for him. When I asked if the bright stage lights bother him, he responds, "Yes, but I never look in that direction. I just look at other characters." His success in drama has earned him a few wins in drama competitions. Walsh-Bowers (2006) asserts, "Social actors adopt various characters, depending on the situation, and different strategies to shape how their various audiences perceive them. The particular form that 'on-stage' behaviour takes is shaped by the individual's self-image, which changes from situation to situation because of the social actor's different roles" (p. 665). Robert feels comfortable when he is on the stage. He says, "I totally immerse myself into being someone else." He also notes, "I just kind of learned the persona that people expect me to have. If I'm walking or standing on a corner I'll want to look cool or acceptable. I do what I call my Steve McQueen walk. I look like Steve McQueen will look." Robert studied his role to the point that he became Steve McQueen, Lenny, or anyone he admired. He stepped into the role and gave it 100% each time.

Off the stage, Robert wanted others to see him as a regular person. Buss and Briggs (1984) note, "Social behavior is often the outcome of a compromise between external demands for conformity or maintaining appearances (self-presentation) and one's personal needs, impulses, and dispositional tendencies (individuality)" (p. 1311). Robert felt very comfortable on

the stage. While on stage, he was another character, someone the audience came to see, and he gave his all for the audience. Off stage, however, his opportunity for identity creation suffered.

### *Transitioning to College Life in the Shadows of Isolation*

Transitioning to college can be difficult for young people. Everything is so new. Moving to an unfamiliar environment may make a person uncomfortable. The protective place where you received social and emotional support from people you knew and trusted is now miles away. In order to navigate this new environment, you must interact with strangers to seek help or determine who you can trust. Finding a group to fit into takes some time and work. You have to build relationships all over in this new place. For Aspies, that is a huge challenge.

Walter attended a large college. Although he felt somewhat isolated on such a large campus, he developed a small circle of friends. However, depression and chronic anxiety emerged during Walter's college years. How does one concentrate on coursework when feelings of depression sometimes take over? Eldeleklioglu (2006) writes, "In cases of insufficient social support or perceived so, an individual feels him/herself lonely and out of support and this in turn creates a good environment for depression to show itself" (p. 745). This new challenge, along with navigating student life on the campus and in the classroom, took a heavy toll on his already challenged life space. Walter had so much to look forward to and so much to offer. Yet, depression set hurdles in his path, which made daily campus life more isolating. Although Walter was out of his comfort zone, he took a chance to dwell among his peers. Walter's academic ability earned him a space in a major university.

Rice, Leever, Christopher, and Porter (2006) project, "Gifted, talented, or otherwise high-achieving people in roles or activities in which performance expectations are likely to be high would be expected to be especially attuned to their adequacy in meeting such expectations" (p. 525). But for Aspies, the transition does not happen with the same end results. Walter attended a large university unlike his high school. Being the brightest student in high school changes when one is among hundreds of bright students from all over the globe. The academic bar is raised and students may not shine as bright as they did in high school. Along with the academic demands comes the need for social connectedness as students orient themselves to this new environment. One has to find his or her place by connecting with others who share common interests and provide social support when needed to reach visibility. For Aspies, this is a special difficulty.

Wei, Russell, and Zakalik (2005) note, “If deficits in social competence experienced by lonely freshmen college students can be identified, then ways of helping them enhance their social competencies in order to build satisfactory relationships might be developed, thereby decreasing feelings of loneliness and subsequent depression” (p. 602). When Walter entered college, he notes, “There were the stresses of being on my own suddenly, without the usual support systems.” He had to figure out the maze of college life on his own, and without the social skills to do so. What is this new experience like for a student who had a support network for most of his life and is now expected to advocate for himself for the first time in his life? How does one begin to problem-solve daily encounters in an overwhelming environment without the usual support of family and friends? Walter stepped outside of his comfort zone to minimize his feeling of isolation. He found a small circle of support among students who shared common interests. This circle of support became a new safety net. He found a group that he was able to fit into on campus. Also, he became a DJ on the campus radio station. He was a voice on the campus, and yet his voice held a hollow resonance as far as connecting with friends.

Arthur carved a place for himself on campus with others he identified with to enjoy the college experience. He reveals:

In college it had – kind of most of the people I hung out with well, you know, of the same kind of common interests. So there was never a conflict there. There were of course people who insisted on calling me a freak all the time, but I never cared because, first-of-all, when I did interact with them, so why do I care? And two, every time it’s – I was actually ever close enough to them, like within harm’s reach vicinity say, they’d shut up. (Arthur)

While in college Arthur also participated in theater. He mentions that he did not have a problem adjusting to college life. Yet, some people called him a freak. According to the *Webster’s Unabridged Dictionary of the English Language (2001)*, freak means “odd” (p. 762). Although he said that he did not care, how does a person brush off such ugly words? Arthur’s early years of fighting and ending up in the principal’s office may have helped him to create a wall of defense and not allow words to penetrate. He knew children used words to taunt other children. As an adult, he was aware that people sometimes use hurtful words indirectly. Arthur did not allow these words to penetrate the way they did when he was younger. Nor did he allow

words to impact the way he feels about himself. He has maintained his own identify. Or has he? How does he view that identity? Although words bothered him in the past, as an adult, he has learned to handle such situations differently. Arthur seems to be comfortable with himself. He does not allow other people's perception of him to impact how he navigates daily activities or his way of being.

Arthur attributes his success in college to finding others with common interests. He also feels that there were less cultural antagonisms on the college campus. Shirley found her place in a community college music course. She learned to play the piano. She has found a few interests that fit her. Since leaving college, she has continued to play the piano in her place of worship. Shirley goes to the gym and walks a few miles a day within her community. She enjoys listening to a variety of music on her iPod.

Arthur, George, Robert, Shirley, and Walter tried to follow the many "neurotypical" footprints of daily life. Sometimes, their footprints appeared to be a good fit. Other times, these Aspies had to make their own footprints to find place. Usually, the comfort of the footprint does not last long. Therefore, their journeys continued until they were able to imprint their footprints comfortably in the landscape among the "Neurotypicals." How long does one have to journey through the numerous footprints in life before he or she finds a place to call home? Aspies' motivation stemmed from their desire to be with others and be treated like everyone else. Once an individual with Asperger's Syndrome finds that welcome fit, he or she can build place and find visibility.

College prepares young people to transition into another stage of life. That stage is the world of employment. Young people put what they learned within the walls of higher learning to the real test of not only competing in the job market, but obtaining and maintaining employment in order to live independently. Aspies share their employment experiences.

### Employment Tales

Employment is a part of most adults' life. We prepare ourselves for specific careers and apply for positions in various employment fields. While already employed, we may seek other opportunities that may become available within the agencies. Some people may establish their own company, completing a personal dream. Becoming employed begins with the interview process. This is an opportunity for an individual to sell his or her abilities and talents. The

interview process may be compared to that of a salesperson persuading the customer to purchase a particular product. The product is the interviewee. The abilities and talents are the characteristics of the product that employers seek. Finding employment can be a difficult process for anyone to maneuver. People with Asperger Syndrome not only have a difficult time obtaining employment, they also have difficulty maintaining tenure on the job.

Mawhood and Howlin (1999) explain, “Even if individuals are successful in getting through the interview process (a major stumbling block for most), jobs tend to be of low status and/or to end prematurely – often because of difficulties related to social competence” (p. 230). How do Aspies maneuver the interview process? How do they get a foot into the doors of employment? What is it like for an individual who has difficulty with social interaction to navigate the daily routine of an office? Attwood (2007) writes, “Although the person with Asperger syndrome may achieve academic success, difficulties with social skills may affect his or her performance at a job interview, the social or team aspects of employment, or understanding of social conventions such as standing too close or looking at someone too long” (p. 22). Personalities, work expectations, interactions with both supervisors and co-workers are just a few challenges that people with Asperger’s may face during the workday. Experiences of the participants in the workplace show their efforts to be like their co-workers; they strive to be contributing members of the team, but for these five Aspies they are in a place they felt that did not always understand their needs.

### *Between the Doors of Employment*

Getting in the door of employment takes planning and work. Applicants come with many skills and experiences, that for some, create a competitive edge. Employers want the best person for the job, and they take great care screening applications until selecting persons to interview. This process puts the applicant to the test of demonstrating and proving that he or she is the best person for the job. Generally, the applicant will not be aware of the style of the interviewer or interview questions, or even the number of people conducting the interview. Anticipating what questions the employer may ask and what the employer may be looking for in a new employee is difficult to determine. There the applicant wants everything to be right including the right attire to impress. Still, being interviewed will cause most individuals to experience some anxiety and even sweat. For Aspies, the interview creates a monumental challenge.

Heidegger (1962) writes, “Anxiety is not only anxiety in the face of something, but, as a state-of-mind, it is also anxiety about something” (p. 232). For people with Asperger’s Syndrome that something is the unfamiliarity of the setting and not feeling at home. Casey (1993) suggests, “We feel at home right away in certain built places, while in other such places a lifetime of residence will not lead to any comparable sense of at-homeness. The ‘somewhen’ is as radically indeterminate as the ‘somewhere,’ and both escape the confinement of purely quantitative determination” (p. 179). During the interview there is no script to follow nor are the interview questions provided in advance. The interview may be structured or conducted in an off-the-cuff method. Although others will approach the interview process in this manner, according to my participants, it will cause significant anxiety for people with Asperger’s Syndrome.

Hurlbutt and Chalmers (2004) state, “Another factor affecting employability was communication issues” (p. 219). After interviewing six adults with Asperger’s Syndrome on employment, one adult named Rosalind, shares her experience about the interview by stating, “She had to practice and rehearse different things to say when she went for a job interview – how to say it” (p. 219). Attwood (2007) suggests, “The person may need to rehearse having an interview and discuss with someone who knows him or her well whether to accept a particular offer of employment” (p. 298).

The participants state that the interview process has been a barrier to their employment. The unknown creates anxiety for everyone who has applied for a job. Yet, for these individuals with Asperger’s, the traditional interview process has not allowed them to articulate their skills and experiences in the manner that worked for them. Participants indicate that one-on-one style interviews seem to work best for them. They had difficulty understanding what goals in five years had to do with the present job. They want questions geared toward the job, not future endeavors.

I don’t interview very well. That’s an obstacle. Once I’m on the job, I get glowing reviews. Everyone likes me. I do a great job. That’s why at interviews I really push my references. (Robert)

When I asked what made the interview such an obstacle, Robert responds:

If I could figure that out, I could fix it. Well, actually, it depends on the type of interview, and I just recently realized that I have not had—I've not given a good interview, not even once, since moving to Virginia.

And the only good interviews I ever had were in Texas. And in trying to think that through, it seems to me that it's because in Texas they give different kinds of interviews. Here in the D.C./Virginia area I was asked questions—what I call syntactical questions. “What is the syntax for doing this,” or technical jargon.

Robert describes the interview as an obstacle. According to *the Oxford Concise Dictionary of English Etymology* (1996), obstacle comes from the Latin word *obstaculum*, meaning, “stand in the way” (p. 142). Communication and social skills deficits often stand in the way of the individual presenting his or her true abilities and talents. Robert was confident in his ability to perform the essential duties of the job. However, he knew that during the interview process, he did not present himself as if he were as knowledgeable about the position as his resume stated. Therefore, Robert learned to rely on his references to speak for him when he applied for employment.

So, I'm self-taught. I do the same things, but I might call it something else. So, their questions would confuse me 'cause they're using this buzz word, computerized jargon that I'm not familiar with.

Whereas in Texas, I was asked more philosophical questions. “Tell us about a time when you were faced with this kind of problem,” and I'd tell 'em about that and kinda the solutions I came up with, and they were very impressed with that. (Robert)

Robert's experience with interviews has helped him to figure out what worked for him. According to *Webster's Unabridged Dictionary of the English Language* (2001), interview comes from the Middle French word *entrevue*, meaning, “to glimpse” (p. 999). The employer uses this meeting to assess the skills of interviewees to find the best-qualified person for the job. Interviewees use this meeting to seek further information about a position and the company before accepting employment. However, it is difficult to present your best when you do not understand what is being communicated. Robert wants to be presented with a problem so that he can demonstrate his qualifications for the position. He is comfortable using a holistic approach to

solve problems. He has learned to weigh the situation to come up with a solution. His rationale was that an employee who has the ability to problem-solve would be an asset to a company.

Arthur shares his thoughts about the interview process.

I think one-on-one interviews are the best. One of the reasons why finding appropriate work for us could be difficult is for our interview skills, that it's something that could distract us.

Dealing with direct questions that are relevant to precisely what you're doing and so forth work well, rather than these ridiculously open-ended questions like, "Explain a time where you did this, or where are you going to be five years from now?" (Arthur)

In response to my concern that the open-ended questions of this interview, like employment interviews, may be creating a problem for Arthur, he responds, "I get so used to those questions, it's just par for the course. It's – it's just a – they're not helpful in terms of if you are looking to hire me to do this. Why are you wasting your time and my time worrying about this thing later on? Focus on the subject at hand."

People with Asperger's Syndrome, like Arthur, approach the interview process differently. Although most of the participants prefer a one-on-one interview, employers do not offer applicants a choice which raises the question, how should a person with Asperger's Syndrome who favors one-to-one communication prepare for an interview? Syntactical language makes little sense to people with Asperger's Syndrome. The interviewee has to be prepared to converse with one or more members of a company each time they are invited to interview for a job. Also interview questions that are simple and direct make more sense and are less confusing to them. However, they must learn to respond to a variety of questions, including questions that allow them to speak to their abilities, experiences and strategies for solving problems.

### *Getting Through the Day at the Office*

Every office has policies for employees to follow. These policies usually are given to new employees. Written policies generally can be found in the personnel office or online for all employees to access and review when needed. However, there are some general office practices that are not found in any policy manual. These practices are called unwritten rules that are practiced in work environments. Each office may have a different set of unwritten rules, but

nonetheless, they are in place. Those who are unfamiliar with the unwritten rules often become familiar with them through trial and error. Attwood (2007) writes, “There can also be issues of not accepting conventional procedures, and difficulties with time management, and recognizing and accepting the organizational hierarchy” (p. 22). These unwritten rules are part of office culture. For example, some companies may encompass a culture that has a strict dress code and office guidelines, while other agencies may be more relaxed with those same office guidelines. Unwritten rules may or may not be mentioned in the interview process. Unwritten policies may include social activities as well as work assignments. The participants share a day in the life on the job.

When asked about getting through a day at the office, all the participants had an example or experience that they could share that happened at work. Shirley remembers vividly when her supervisor asked her to do a project. According to Shirley, as soon as she began the project, her supervisor gave her other tasks to do. The supervisor began asking her if she had finished the original project. Shirley became frustrated and began to cry. Her supervisor told her that crying was unprofessional. Shirley responded by telling her supervisor that she had been unprofessional too.

When the day-to-day duties of the job became too overwhelming, Shirley grew frustrated. She found that the multiple tasks and immediate timelines presented a confusing situation for her. She says that she became confused over which task to tackle first. Shirley was having difficulty prioritizing her assigned tasks. What is it like to be so frustrated with a situation that all you can do is cry? According to *Webster’s Unabridged Dictionary of the English Language* (2001), frustration comes from the Latin word *frustratus*, meaning, “a feeling of dissatisfaction, often accompanied by anxiety or depression, resulting from unfilled needs or unresolved problems” (p. 772). Shirley was anxious about the number of tasks given to her all at once. At times, every worker experiences an overload with work assignments, but may seek assistance or think of a strategy to work through the tasks. For Shirley, her line of defense was to attack the supervisor and to cry.

Walter analyzed his situation differently. While he saw one boss as a potential bully, he also saw the human side of a different supervisor.

Well, I had a wonderful boss, the most understanding boss you could ever ask for. But I remember one time when — I can't even remember what the problem was. I made some mistake and my boss called me privately into his office and he — I wouldn't say he erupted, but he was clearly angry at me for my inability to do certain things. But that was the exception. That was the only time he ever did it, and again, he was the best — he was, I think the best boss I've ever had, the most understanding, also very interesting. (Walter)

Well, there was a boss who was an out and out bully. And I've read that one out of six people in the workplace will experience bullying, and that includes all people in the workplace, one in six. I don't know whether that announced statistic is accurate. In this case the fellow, he was a serial bully. He bullied several people before me. So in a sense, I didn't take it personally, but he clearly preyed on people who had very little self-assurance, people who tended to be nervous. (Walter)

The workplace can be a challenging place. Supervisory styles will vary, as in Walter's experience from an understanding person to a bully. How does a person with Asperger's Syndrome find balance between the two styles? What is it like for a person with Asperger's Syndrome working in an office with an air of tension from supervisors? Walter is able to function through the tension in the office knowing that he was not the only one singled out. His co-workers also know what it is like to experience bullying. Generally, workers do not have a choice in selecting their supervisor, and an employee has to adjust to the person in charge or in the supervisory role. Walter made the adjustment in order to maintain his tenure.

But, in terms of having a real boss who didn't bully, who just in the nature of things, I think I had one boss who prided herself on her intellectual capabilities. And I don't think she had the intellectual capability she aspired to, but I knew what buttons to push, and I think that was largely because of the intellectual gifts of the Asperger Syndrome. I have encyclopedic knowledge. It's largely applicable to areas this woman was interested in. So I knew how to flatter her, because I would provide information to her. (Walter)

And she was a very difficult woman to get along with in general. She had a very high staff turnover, but I was able to survive there by using my intellectual knowledge to flatter her. (Walter)

Walter has characterized the person he considered a real boss. What made her a real boss? How did she differ from Mr. Understanding and Mr. Bully? Walter describes the real boss as having a sense of his intellect and he used it to his advantage. Walter feels that his intellectual abilities helped him to survive on the job and kept him in good graces with the supervisor. Walter was strategic in his use of his encyclopedic knowledge when interacting with this supervisor. In his conversation, Walter indicates that he had to work twice as hard on the job, but he was able to maintain his employment tenure at the company. He found his place in this employment game. Arthur was not so fortunate.

One thing is that I work on a different floor from the floor where they store the financial information. So I have to go up and down through the halls to get what I need and bring it back. And one meeting I had with my supervisor, he was telling me that I should spend less time in the hallways, because people in the other offices are noticing that and complaining about me wasting time in the hall. And I pointed out that I'm not wasting time. I'm doing work, first off. Second of all, I think that if a person has a problem with something I'm doing, they need to come to me about it instead of going over my head. And that's pretty much it. (Arthur)

Arthur's work culture seems to be controlled by supervisors and his co-workers. Imagine working in an office where your co-workers confront your boss regarding your whereabouts during the day. This practice was not acceptable for Arthur. How did his co-workers expect him to do his job if he did not have the necessary materials? It was impossible for Arthur to do his job without the necessary materials to complete the assignments. For some reason, his co-workers had the impression that Arthur was not working, all because of the many trips he took to the records room during the workday. Arthur does not understand why his co-workers did not speak directly with him about their perception of him not working. How does a person find place in a work environment when he or she knows that work peers are watching them? According to *Webster's Unabridged Dictionary of the English Language* (2001), the word watch comes from the Middle English word *wacche*, meaning, "to keep under attentive view or observation" (p. 2146). It was apparent that Arthur was unaware of his co-workers' concerns until his supervisor informed him.

George's issue was the opposite—not being around his peers at all.

Well it depends. My last job was very boring and I didn't do a good job there. That was intentional so I got fired, and I've been unemployed for ten months. My last job I was just isolated in my apartment, and I was looking up Securities and Exchange Commission filings on the computer. I would look at hundreds of them a day, and some – write some and e-mail some to some of the other reporters. So only once or twice in a week would I ever talk to anybody for the job. I was very isolated. (George)

George talks about working in isolation. George did not mention if he worked on a team or alone at his office. While Robert spoke of isolation, too, he keeps company with the pictures in his head.

Well, being a computer programmer, I found that autism has brought me what other programmers don't seem to have. Temple Grandin has talked about thinking in pictures. And not just pictures but three dimensional pictures that we can walk through. And that's my way when I'm in a meeting and a client is discussing their needs, in my head I'm actually inside the computer in a 3D scene with all the screens in the program that's coming together. (Robert)

What is it like to think in pictures? According to *The Oxford Concise Dictionary of English Etymology* (1996) defines, picture comes from the Latin word *pictūra*, meaning, “mental imagine” (p. 352). Robert knows the computer inside out. He reflects on his ability to troubleshoot computer related problems mentally. This process allows him to arrive at solutions. He does not need a diagram of the computer. Instead, he pictures the inside of the computer in order to understand how it functions and to problem-solve. His way of thinking was quite different from that of his colleagues. According to the *Webster's Unabridged Dictionary of the English Language* (2001), think comes from Middle English word *thenken*, meaning “to analyze or evolve rationally” (p. 1971). Robert was satisfied with his diagnostic system of handling a computer problem. For him, this is more than a job; it is his career. Robert continued to learn more to update his skills. As he talked, the passion for his job was unmistakable in his face. Working through the daily routines of the office is only a part of functioning on the job. Developing coping skills is important as well. Getting along with others on the job and participating in social events can also be a deciding factor for one's tenure.

### *Functioning in Employment Placescapes*

Work related issues can become overwhelming. Sometimes, work related issues may be solved, and other times, they may lead to termination. Many offices provide employee assistance for work related issues, and it is available to all employees. Often, those barriers continue to mount as people with Asperger's attempt to fit into the work environment.

One barrier for new employees is getting past the probationary period which can be as short as three months or as long as one year. When a person is selected for a position, he or she wants to do the best job possible. People want to maintain employment in order to have financial and personal independence. The probationary period can be a challenging time for people with Asperger's Syndrome if they do not have support within the office environment. Some people with Asperger's may lose their job because they may not be able to meet the expectations of the job.

George states, "Nervousness has led me to losing jobs." George wants to work but is unable to maintain employment for a long period. He talks about the longest period of time he spent on a job as being a year and a half. Walter responds, "I think there are certain problems in terms of concentration where I didn't take the right medication for anxiety. It's nervousness, lack of self-assurance that has hurt me at work. Those were problems. It was easier for me to get jobs than to maintain them." How can a person demonstrate ability on the job when he or she constantly feels nervous? Self-confidence is a skill that employers look for when hiring employees. Hoel (2004) projects, "Conscientiousness and emotional stability also have been found to predict an individual's propensity to remain on the job" (p. 25). Both George and Walter enjoyed working in their chosen career fields. Yet, their work skills alone were not enough to keep them on the job. Their nervousness appeared to go on long enough to signal attention in the office. According to *Webster's Unabridged Dictionary of the English Language* (2001), the word nervousness comes from the *Latin* word *nervōsus* sinewy meaning, "highly excitable; unnaturally or acutely uneasy or apprehensive" (p. 1289). Employees displaying nervousness may cause others to feel uneasy in their presence.

The tradition of staying in one career for 30 years has changed over time. The length of time an employee remains in a career field varies among people. Today, an individual may change careers as often as he or she feels necessary to keep up with the ever-changing

employment market. Change is a big challenge for people with Asperger's Syndrome. Both George and Walter talk about encountering changes that interrupted their normal work routine or stress of a certain work assignment. How does a person who is "change challenged" transition and find place in such a changing employment market? Traditionally, employers desired employees that possessed skills, social competence, and longevity. Wilson (2006) asserts, "Collectively, it appears that most organizations look for candidates who demonstrate strong character traits, particularly integrity, leadership, flexibility and a strong work ethic" (p. 33). The participants with Asperger's Syndrome share their experiences regarding duration in the job market.

When asked about the longest length of time on the same job, experiences of the participants varied. The longest time Robert spent on a job in his adult years was nine years. Robert notes:

But as a rule, so far it seems to be amazingly consistent that I usually stayed about nine years at any given job in my adult life. It's not like I decided, or I get tired, or I quit or things of that sort. The most recent time they were having corporate layoffs. I had absolutely no control over that, but it, again, was approximately at the nine-year point. So, it just seemed to be a coincidence.

The longest period of time that Walter spent on a job was two and a half years. For Shirley, it was three years and four months, and for George it was a year and a half. Arthur shares that his longest period on a job is his current one of two years.

Arthur and Robert indicate that the shortest period that each of them have been employed was two weeks during their adolescent years. Robert left the fast food industry because he felt that he was treated unfairly. Both Arthur and Robert note that because their parents were still supporting them, losing a job at 15 years of age does not have the same impact as it would have had if being terminated from a job at age 25. Shirley says that the shortest period of time she spent on a job was one month, and for Walter it was a year and a half. In their opinion, their careers may have not lasted as long as their neurotypical colleagues, not because of inability, but rather because of inflexibility.

## Playing the Social Part on the Job

The workplace may celebrate different occasions throughout the fiscal year: weddings, births, birthdays, work anniversaries, promotions, farewells, and holidays. These may be big events or just water cooler celebrations. Along with the celebrations, come barriers and issues that may arise in the work environment.

Socializing on the job may be one of the unwritten rules employees are expected to follow. The participants know firsthand that they need to play the socialization game, although it is uncomfortable for them.

### *Playing to the Team*

Workers are expected to be team players on the job. For some people, the role of team player comes natural. Yet, some people may have to work harder than their co-workers to achieve that same goal. They have to play the game to live up to the social norm of the office. The participants recall their experiences of playing the socializing game at work.

Oh. I think there were a couple of times where – just coffee with– water cooler type conversations. (George)

George did not mention participating in any of the celebrations listed above. Nonetheless, he did mention water cooler conversation as a social activity that he participated in while on the job.

Well, we talk. The co-workers, they're reading books, so I just stay to myself. I just ask questions. I just talk a little bit. We'll talk about the weather. We talk in terms of family. (Shirley)

Many offices have a break room or area just for employees. That room is often a place where employees can relax and where social activities occur. Shirley is an avid reader and often reads during her break. Silence is expected in a space filled with readers. Although Shirley says, "We talk," it appears that she may not be able to gauge when is the right time to break the silence to in order to communicate with co-workers.

I have participated in social activities on the job, but I have pursued activities with former work colleagues. We sometimes have pro forma birthday parties at the office. Office parties wouldn't necessarily be so much from the heart. (Walter)

Walter's participation in office parties occurs as a professional expectation. It is an unwritten expectation that all employees participate in social events in the office. Walter is aware that his attendance is an expectation. He does not want to take the risk of co-workers noticing his absence at social events. Instead, Walter goes along with the group despite his true feelings.

To explain that I'd have to explain that I'm a contractor. And the government people, they hang out with each other all the time, and they throw their parties and so forth, but it's kind of like they have their little group, and we have our little group, and the two generally don't mix socially. (Arthur)

In some work places the employees are divided by rules and responsibilities. This may extend to social interaction. Both groups may share the same work space, yet, exist in different worlds (Aspies and Neurotypicals). It is understandable that the two groups may not share shoptalk since they are from two agencies. However, these people spend as much time with each other daily as they do with their own family. Arthur upheld the unwritten office policy of not mingling outside of his group. Robert confronted the social interaction in a different manner.

As a general rule, just the luncheons that they occasionally sponsor, and I don't really talk that much during those. Just recently, my wife and I went to an engagement party on the weekend for a co-worker of mine, which was something I don't think – I don't recall ever doing before in my life. It was like one of those social experiments to try to get out of my shell — but as a general rule, I don't interact much. I sit at my desk and have earphones on, and one of my co-workers called me the most quiet person he's ever met in his life. So, it's usually just very minimal social—in fact, I even go to the luncheons just because I know what's expected. (Robert)

I don't go 'cause I wanna go. I'd rather stay at my desk, but I just figure it looks good. It helps my career, and I socialize some 'cause most people are not fired because they can't do the job. They're fired 'cause they can't get along with their co-workers. So, I try to do things like that so—just to show that I can get along. (Robert)

Robert understands the significance of playing the socialization game in the office. He plays the game to demonstrate that he is a team player, although he is most comfortable with silence, his comfort zone. When social events occur, he would spring out of his shell. Bachelard (1994) writes, “A creature that hides and ‘withdraws into its shell,’ is preparing a ‘way out’” (p. 111). Robert’s “way out” of his shell helped him to remind others that he was present and a part of the team.

### *I Am Doing My Best*

According to the participants, interacting effectively with co-workers continues to be an employability skill they have difficulty with performing. They view interaction as a two-sided coin. These Aspies share what they want from their co-workers.

Stay professional. That’s really the only thing I ask. People with Asperger’s don’t like chitchat. They don’t like to waste time. Even when I’m fiddling, I fiddle by myself. I don’t like fiddling with other people. (Robert)

So—and just—and the only thing I don’t like with where I’m sitting now is I’m in kind of a common area. Sometimes, the chitchat of other people gets really annoying. Even when—especially when they get louder than what I’m hearing in my earphones with my iPod. (Robert)

Some Neurotypicals may get annoyed when interacting with Aspies. Aspies get annoyed too. Imagine working on a project and someone stops by your desk to have small talk that seems endless. How does a person balance work and social competence on the job without looking like an introvert? Robert plays the social game when necessary. He puts on his earphones at work which is a signal to his co-workers that he does not want to talk. He is willing to play the socialization game when necessary; in return, he wants his co-workers to respect his space.

Half the battle of employment is getting in the door. The other half is maintaining employment. Not only do employers want employees who can perform the task, but employers also want those who fit into their company’s culture. Lee, Johnston, and Dougherty (2000) express it this way, “Those who are less extroverted (i.e., more introverted) tend to be more reserved, have a lower energy level, and are less likely to experience positive feelings” (p. 420). In other words, employers want employees to get along and work well with co-workers. Lee et

al., (2000) proclaim, “Agreeable people are inclined to be polite and friendly, which facilitates teamwork and workplace functioning” (p. 421). Today’s businesses operate in teams. Therefore, one can assume that regardless of how qualified an employee is to perform a job, being a team player is just as important a qualification. A person has to get along with co-workers in order to complete the job.

Individuals with Asperger’s Syndrome seem to work best by themselves, as the excerpts from Robert reveal:

And at both this job and my previous job,—both jobs, I was very successful at and they were basically, they said, “Okay. This is the project. This is when it’s due by. We’ll see you then,” and no one looked over my shoulder in the meantime, and I was usually a week or two ahead of schedule. (Robert)

Being micro-managed by a supervisor may signal to some people that the supervisor is not confident in their ability to perform a task. What is this experience like for Aspies in particular? Looking over a person’s shoulder is like a shadow being cast over the person from the beginning to the end of a project. According to the *Webster’s Unabridged Dictionary of the English Language* (2001), shadow comes from the Middle English word *shadwe*, meaning, “a reflected image” (p. 1756). This lingering image may cause the person to feel uneasy. This experience may create a level of anxiety until the project is completed. Aspies already have too many shadows of insecurity. Robert did not have this issue, however, and he was grateful.

In her past work experiences, Shirley became frustrated with both assignments and given time-frames for completion. She indicates that she likes the team approach on the job. According to *Webster’s Unabridged Dictionary of the English Language*, team comes from Middle English *teme*, meaning, “a number of persons associated in some joint action” (p. 1949). The team approach seemed to provide a support system on the job. Maybe teaming is a way for Shirley to ask for help rather than confronting the supervisor.

The participants express how employers could support them on the job. They are not asking employers to change the policies to fit Aspies, but they want employers to understand their style of navigating the world of work to be successful and contributing members of the workforce.

When it comes to actual work and job skills, that's never been too much of a problem. It's—people have a tendency to like working with people who they're comfortable with people who are more like them. So, if people understand, like employers, for example, that someone with Asperger's is—they're doing their jobs and all, they—there's no need to expect them to be the life of the party at whatever office Christmas celebration is going on. Just realize that they'll do the job just fine. They're just not necessarily going to sit around the water cooler and chitchat a lot, which is one of the things that make people uncomfortable in the first place. (Arthur)

Arthur wants employers to accept him just the way he is. He just wants to do his work. The choice was clear when it came to socializing or doing a job. Yes, he may have attended a social gathering, but did not call much attention to himself at the gathering. You will not see Arthur wearing the lampshade doing the cha-cha at the office party.

For George, getting the job done in a relaxed atmosphere worked for him. He suggests that both employers and co-workers can “Just to try to be more understanding, to cut ‘em more slack.” According to the *Oxford Concise Dictionary of English Etymology* (1996), slack comes from the Old English word *slaec*, meaning “loose” (p. 442). Companies cannot operate in a loose manner and survive, nor in a very strict, inflexible environment. The bottom line is getting the job done.

Shirley wants cooperation and feedback from both the supervisor and co-workers. She tells me how she learns in a work situation.

You know, well, my way, I just learn something new, learn different duties, and also what I did, working at night, shelving books or something, like, in different areas, and that my boss test me on certain things [sic]. (Shirley)

Receiving support helps her to be successful on the job and reduces her frustration when she does not understand an assignment. Natural support from co-workers will allow her to ask questions in order to get an assignment right before handing it over to the supervisor. Arthur, on the other hand, recognized tensions that can result from co-workers with Aspies in relation to tasks needing to be done.

But sometimes—if you are working on something, and someone else is working on something, and you're not given more work, it's not a sign that the boss has lost faith in you, and there's a kind of reverie going on. It's just because this person with Asperger's has, due to their unique abilities, a better way of doing this particular thing. But before you get upset and try turning it into a competition, keep in mind that you also have skills at things that they don't have, so your input is just as valuable. No one's trying to shortchange you. Likewise, if you're the one getting more work, and you're neurotypical, that's not because you're being picked on. (Arthur)

It's because this is something that you are able to do more efficiently, so think of it more in terms of you have this set of skills. This person with Asperger's has this set of skills, and the idea is to respect that there's some give and take in what you do, and it's not that anyone is either shortchanging you or trying to take advantage of you. It's simply a matter of how is the best way to get the job done, and if your Aspie co-workers may seem a little insensitive, the reason for that is because they don't necessarily understand everything that's going on in your area, and it's not deliberately malicious. So, if you explain that to 'em and let them know what's really going on, most of the time they'll be more than happy to help you or to at least do what they need to do to help the situation. (Arthur)

Arthur understands that getting the job done is very important. He also understands that each person comes to work with skills. Skills allow a person to do the best job possible and contribute to the company. Arthur feels that there appears to be a lack of understanding on the part of both the Aspies and Neurotypicals when it comes to skills versus balanced workloads. Although this decision is not intentional, it may be taken as such by some employees who feel slighted by the supervisor's decision.

Walter states that support for Aspies goes beyond employers and co-workers. This gets back to more news media coverage of adults with Asperger's. Without more news media coverage of the problems of adults with Asperger's, there won't be so much public understanding of the problems of adults with Asperger's. (Walter)

There is still a silence among the public in regard to understanding people with Asperger's Syndrome. Walter feels that the silence hinders the public from understanding the needs of Aspies in order to support them and give them a voice on the job and in the community. Renty and Roeyers (2006) support Walter's claim, "Further, given the significant association of quality of life with the number of unmet formal support needs, professional supporters should strive to meet all individual needs that persons with ASD report" (p. 521). In the previous section, the participants shared socialization activities on the job. The next section looks at the strategies people with Asperger's Syndrome use in the community.

### All the Worlds' a Stage

Lights, cameras, action! The stage is a place where people can act out the lives of others. It offers a person a place to master the art of fantasy as well as true life. The curtains rise and the show begins. You mastered your line and step into character. Written scripts come to life. The spotlight is on you; the center of attention and the show begins. Sometimes, the acting continues when the curtains fall. Some people transfer acting skills from the stage to their daily lives. The world becomes their stage. The Aspies in this study share how they use scripts to maneuver the social maze.

#### *Script Please!*

Hollywood and Broadway are not the only places we find actors or people using scripts. In fact, each one of us has acted or used a script at times to communicate our happiness or dismay with others. Sometimes, we write what we want to say; other times we mentally prepare a script. Then we practice and rehearse a few times to make it perfect before we actually deliver the message. Using scripts is a strategy that many people with Asperger's Syndrome use to navigate daily life. Much of our daily life revolves around socializing, and individuals with Asperger's Syndrome are very aware of that fact. They try to blend into the crowd, but it is hard work. Therefore, scripts and acting are valuable tools that assist people with Asperger's in their attempt to stand closer to the Neurotypicals, instead of standing apart from them. Aspie adults share their social scripts as they try to blend into the neurotypical world.

Some people find it easy to fit into any placescape. At meetings, parties, or in crowds they move around smiling and introducing themselves to strangers. Like magic,

people smile back and open up to them. Within five minutes, a stranger might think that they had been friends for years. What is this secret regarding communication? Three of the participants talk about masking or acting as they attempt to blend into the neurotypical crowd.

I act, basically, almost all day long. (Arthur)

It's kind of like—it's not something where you can waltz around the stage for two hours and then go back to the dressing room and not do it anymore. It's something—it's an act you have to keep up all day, so it is very draining, but it's just something that needs to be done. (Arthur)

What is it like to be on stage all day? Arthur believes that he has perfected his daily stage performance. Buss and Briggs (1984) say, "Social behavior is often the outcome of a compromise between external demands for conformity or maintaining appearances (individuality)" (p. 1311). Arthur does not want to stick out in the crowd. He wants to fit into the neurotypical world. Acting is what Arthur is willing to do to a point. He describes acting in this way.

And you can keep up an act pretty well for most of the time that you need to. The difference is that when you start getting into a relationship, you're spending more time with this person, and I don't care if you are Brad Pitt — you can't keep up the act – 24/7. At some point, you need to be able to recharge, and at some point, the illusion fades. So, for a real relationship, you kind of have to drop the mask, and there's more honesty and trust involved than just a normal social relationship.

Arthur knows that there is a time and a place for acting. Wearing a mask on the job or in a social setting is one thing. For the most part, social activities in these settings may be superficial in nature. He understands that in order to develop a close relationship, a person has to move beyond the scripts to let the true person come through. Arthur believes that exposing one's true self when developing a relationship can create openness and enhance longevity. Walter illustrates how to act natural in his interaction with co-workers on a daily basis.

I've managed to hide my – I've managed to hide my shyness sometimes. It's been more difficult in the workplace. (Walter)

Well, I try to find out what other people are interested in and talk to people about their interests instead of mine, and that made me more comfortable, actually, because people like to talk about themselves rather than—than talking about other people. That's a generalization, but that's what I think. (Walter)

Walter learned to take the focus off himself when he interacts with co-workers. This creates a perceived balance in communication. Although a subject may not have been of interest to him, he listens anyway. He figured out that if he wants to fit in with his officemates, he needs to be able to show an interest in them and he was able to pull off what he considers an award winning-performance.

Robert has spent years perfecting the role of a neurotypical person. It requires so much practice, so much work to be someone else in order to identify with others.

And since I was 15 in drama class, I've gone through and tried to develop a neurotypical persona so that I look like a neurotypical—I fit in. They don't have any hint that there's anything different going on inside my head. (Robert)

And, mainly, it's—I think that Aspies who seem to always have problems at work do so because they're trying to interact in a neurotypical world in an Aspie way. (Robert)

Robert sees this as a way to belong and not stand out. What does this do to his identity? Robert did not reveal himself as an Aspie in the workplace. He used his Steve McQueen persona to fit in the work setting. This persona allows Robert to have a neurotypical presence in the office.

These men established roles in order to navigate their daily workday. They used scripts to blend into the office culture. They are able to maintain their secret of being an Aspie. Each man found a character role that he is able to step into and blend into the office crowd. Arthur states, "It's something that needs to be done."

### *Chemistry*

What brings people together? People often speak about chemistry when developing a personal relationship. What is chemistry? *Webster's Unabridged Dictionary of the English Language* (2001) defines chemistry as "the interaction of one personality with another" (p. 353). A strong attraction will often bring two people together. The chemistry may lead to dating, and the two people spend time together to get to know each other better. Sometimes, they make a

love connection, and sometimes the chemistry fades. The participants were asked to share their thoughts on developing personal relationships and what it is like for a person who cannot read the body language and gestures of someone they care about.

It's very difficult to pick up social cues, and also people with Asperger's can tend to be a little eccentric, or just a little, I'm looking for the right word, immature, which can turn off a potential romantic partner. (Walter)

Dating is a way to find out more about a person of interest. Some dates blossom into lifetime commitments. Some dates turn sour and end abruptly. Making the right impression is dependent on your interaction and communication with people. Saying the right word means everything when you are building a relationship. Walter speaks to the difficulty of reading social cues. Walter seems to think immaturity has something to do with it, but is it really that? According to *Webster's Unabridged Dictionary of the English Language* (2001), immature comes from the Latin word *immaturus*, meaning "emotionally undeveloped" (p. 956). Wearing a smile is not always a sign that a person is happy. What else could a smile mean? Attwood (2007) reveals, "The person with Asperger's syndrome may have an unusual or immature concept of emotions in terms of understanding that someone can have two feelings at the same time, for example being delighted to have a promotion at work but also anxious about the new responsibilities" (p. 134). Misunderstandings can occur when the emotions of one person do not register with the other. Yet, continued and frequent social interactions are important for social development.

And then there's also what is commonly referred to as chemistry, which I have none. (Arthur)

Well, chemistry is – or what people call chemistry is the ability to interpret a lot of behavioral and physical subtleties and I can't. I noticed in the past two months, for instance, two months, 12 women, not a single one of them. It's like knowing the steps to the mating dance, but not being able to do them or – forgive me for using theater terminology here, but it's what I'm familiar with. You can get your blocking down. You can get your lines down, but if you just can't get your character it does you absolutely no good whatsoever. So it's very frustrating when no matter how good you are, no matter

how nice you are, it's that one element that you can't control that makes sure you always lose. (Arthur)

If you asked couples how they knew their partner was the right one, there would be a range of answers. Couples will often speak of the strong attraction they feel for their mate. It is magnetism. Many people may say, "I knew he or she was the one for me, the minute we met; the chemistry was there;" or "We connected right away." Well, Arthur has a different experience connecting to a partner. He has not found the right chemistry to maintain a lasting relationship. Arthur says that he continues to hear the line, "You are a nice guy, but we just don't have any chemistry." He talks about initial chemistry, but it may not last for long, and he wants to figure out how to reach that chemical balance to maintain a relationship. When Shirley was involved in a relationship, she, too, experienced difficulty maintaining it.

Well I have some experience with life partners and then they didn't work out. Cause I didn't understand that they were taking advantage of me. So my family let me know. Cause sometimes I don't even listen to someone because I have behavior problems. Cause I have some behavior problems. Might get upset. Not being patient. But the things that stress something was bothering me. (Shirley)

Barnhill (2007) acknowledges, "Individuals with AS can find themselves in vulnerable situations and not even realize the predicaments they may become involved in, especially in today's litigious world, with its concern with sexual harassment" (p. 121). When many couples build a relationship, they have an understanding of one another's likes, dislikes, strengths and weaknesses. Shirley has not been able to reach a mutual sense of attraction. Shirley desires to be in a relationship that is mutual, not one-sided. Based on prior experience, she has an added concern of being taken advantage of by her partner.

Although Robert is married, he says that he continues to work hard to maintain his relationship with his wife. He opened up about his experience being married.

Well it was difficult to be married to a person that I'm crazy about and constantly trying to help to be a good husband to her. I wanted her to feel loved. And for her to keep telling me that she doesn't feel loved. She feels that I am a narcissistic manipulative bastard. That everything I do I do for myself. I don't care about people. That you know that when

she saw the rehearsed performance thing, you know that I'd be one way in front of her family. But at home when I'd relax I was a different person in that you know I didn't seem to be listening to her cause I didn't maintain the eye contact. I'm in that relaxed state. And my voice inflections would go flat. She said she thought I was just being dismissive. And she – I don't think it would have been as tough for her if I was like that all the time. But when she sees me in my public persona which is a fake, a put on, she contrasted that with the way I was at home. It was that difference that caused her so much pain. She felt that was indicative of my not caring. When the truth was I was trying more at home to be caring. It just wasn't translating into the way that she was looking for.

(Robert)

Robert loves his wife and tries to be available for her emotionally. However, he thinks his emotions are being misread as acting, and are creating miscommunication between him and his wife. He believes that he is doing his best to maintain his marriage, but his public and personal personas present a challenge for the marriage. Robert acts a role and wears a mask that help him to be one with his neurotypical colleagues. Yet, when he is at home, he takes off the mask. The question became, "Who are you?" Why did he feel that he did not need a mask at home? He comments that playing the two roles becomes both puzzling and annoying to his wife.

How long can a relationship continue when one partner feels unloved and unwanted? Successful relationships are generally built on open communication. Through communication, each partner gains understanding of the other person. "To know me is to love me."

George states, "I've never been able to keep a relationship." Chemical attractions have not lasted long for George. What would it take to keep the attraction going? George would like to know the answer to this riddle.

How can a person with Asperger's achieve chemistry with another individual? A lack of chemistry is the one area that Arthur, Shirley, Walter, George and Robert all feel keep them from being near people they love, as well as people with whom they want to build or keep a relationship. It is an arduous role to play. Chemistry seems to be the tie that connects us with others. However, it seems to be out of reach for these participants.

## Playing the Neurotypical Game

Earlier, the participants share how they took on the role of someone else in order to fit into the office culture. Stepping outside of the Aspie world allows them to blend into the neurotypical world. The neuro role made it possible for them to be another face in the crowd, and they were willing to show another side in order to participate in the neurotypical world. Playing the role of a neurotypical is not an easy task for them. It has taken great effort on their part to be a neuro. Playing the role of a neurotypical is a game that many Aspies play daily. It is a game that gives them place and presence. Each person shares his or her experience of playing the “Neurotypical Game.”

What was it like for a person to feel so out of sync with others? Arthur sees two worlds. Well it's kind of a mutual thing. I know that there are plenty of things that I do that are – may seem unusual for someone that's neurotypical. On the other hand, some real typical behaviors are equally irritating. And when you have a hard time reading people, there's two major problems that that causes. First of all people are very unpredictable. You don't know if someone is a threat or not. So that's one thing to – that you have to keep in mind when you're dealing with someone. So you have to be thinking, “Okay, is this person who and what they say they are, or are they trying to pull the wool over my eyes, or are they – okay. Is that a real question or a rhetorical question.” And if it is a rhetorical question, am I, (a) supposed to say nothing because it's rhetorical, (b) come up with something reassuring because they're upset, or (c) put them in their place because they're sassing me? And you're faced with that sort of generally dealing with people. That always is difficult. (Arthur)

Arthur observes neurotypical behaviors as confusing and hard to follow. Some Neurotypicals may be annoyed with Aspies when they are in their presence. However, the flip side is Aspies also get annoyed by neurotypical's (NT) behavior as well. Each world has its own social language that is difficult for each other to understand.

So as a general rule an Aspie and the NT will go to a party. The NT will feel invigorated by the party. They'll feel jazzed. They'll feel up. When they leave they're just like, “Man, that was great.” An Aspie will go to that same party and even if they've enjoyed themselves when they leave it's kind of like, “Gosh that was exhausting. I am wiped out.”

And will have to go home and crash and decompress by ourselves for a while just to kind of regain our equilibrium. Cause it was so much work to put on that socially acceptable front. I mean it's enjoyable work. But it's work nonetheless. It's exhausting work. Same with teaching. I can stand up and teach for two hours. Go home and be just wiped out. Cause it's just exhausting. (Robert)

The neurotypical game gets more challenging to play the longer the social event lasts. What is it like to put so much energy into acting that you become drained physically? Robert's experience of playing the game is like blowing up a balloon. As long as the air is intact, the balloon maintains its form. However, if the balloon has a slow leak, the elasticity decreases and the balloon's form changes. Robert has put so much effort into being social at an event. He pays the price of losing elasticity as the social event ends. Although the game is taxing on his body, Robert recharges himself to play the neurotypical game again.

Aspies attempt to play the neurotypical game. They try to read body language, but may be unsuccessful. Aspies turn to scripts to enhance their social life. Surely, Neurotypicals enjoy being themselves. Although Robert says, "It's work," he along with the other participants continue to play the neuro game to fit in.

### *You Should Know*

Often, assumptions are made regarding people with Asperger's Syndrome. Neuros who interact with someone who has Asperger's Syndrome may have a different experience to share. Sometimes, a few experiences may generalize across all people with Asperger's Syndrome, not giving them the benefit of the doubt. Those generalizations may keep people with Asperger's Syndrome on the outside of social circles. Aspies in this study share what they want people to know about those living with Asperger's Syndrome.

Just that it's very lonely, and there's a lot of just dealing with life. Well, again, losing jobs I had, being worried about survival, and just being alone most of the time. (George)

George is trying to deal with the challenges that come with having Asperger's Syndrome. Since he is unable to maintain employment, his survival is continually in question. This often amplifies his feelings of being alone. Moustakas (1961) claims, "Loneliness is an organic experience which points to nothing else, is for no other purpose and results in nothing but the

realization of itself. Loneliness is not homelessness. There is no departure or exile, the person is fully there, as fully as he ever can be” (p. 8). George is being in the world as fully as he is able. Yet, he still attempts to establish connections with others. He has an online social network. He feels that this source has been supportive, but he does not mention any friends by name.

Shirley’s challenge is different from George’s. She tries to work through the challenges of life’s transitions. Shirley reveals what she wants others to know:

I’m concerned about my Asperger’s ‘cause I suffer—I’ve been struggling for so, so long—moving into the next phase. (Shirley)

It has been a long battle for her. Shirley attempts to navigate employment and life transitions. She realizes that having Asperger’s Syndrome makes things difficult, and transitions are hard, but she is willing to continue to move on and work through the challenges that she may face.

Arthur wants people to know him and not the syndrome. He prefers a person to be open with him. He says:

I’d like them to know that it’s ah— I’m not the bad guy. I know that if I say or do something that is a little unusual, you know, or not expected, that tends to give people the wrong cues. But I’m not trying to be offensive, and I’m not breaking the rules just for the hell of breaking the rules. If people will let me know what was expected and set the tone for how to work on things, I’m totally, I guess, compliant to learning about that and doing what I can to meet them halfway. (Arthur)

In other words, Arthur wants people to know that they should communicate their expectations to him. He does not want people to assume that he knows the social expectations.

Communication can be difficult for a person with Asperger’s Syndrome to follow. Robert expresses his thoughts about how people with Asperger’s Syndrome communicate this way.

If someone you know has Asperger’s they can’t always tell you what they want to tell you. That doesn’t mean that they don’t want to. It doesn’t mean that they can’t eventually. I think the best way is to have them tell you and you tell them, “Ok, are you saying so and so?” They go, “No, how’d you get that? I’m saying so and so.” You know. And it just takes, the communication aspect takes a lot of patience. Lot of patience. Because we speak very specific, almost scientific terms. A phrase that might just, you

know, that everyone knows that that phrase means so and so. Well no let's get a dictionary. It's like well no the dictionary doesn't say it. You know this is the way it's used. Well if it's not the way the dictionary says it that's not the way I use it. (Robert)

Robert wants people to know that when conversing with people with Asperger's, words may have one meaning for you but may not make much sense to Aspies. He does not want people to think Aspies are being difficult when they ask many questions for clarification. They are just trying to understand and follow the conversation. Robert talks about how people with Asperger's Syndrome filter certain expressions.

It's not gotten to the point where if I'm told that it's raining cats and dogs to go outside and look. You know we're smart enough to know that that's a saying. But, you know there's this rule of clichés and phrases, things of that sort a lot of times we'll come to a completely different conclusion to what you're saying than you think we should. So just know that we take things literally. Very literally. We just don't get this other stuff. (Robert)

Robert spells out how people with Asperger's Syndrome approach idioms. It does not mean that they are less intelligent. Just as words can have more than one meaning, people with Asperger's Syndrome arrive at meanings that makes sense to them. Robert wants people to know how they think, not assume that they should know.

Walter wants more visibility for adults with Asperger's Syndrome. There is little focus on the adult life span, which is where issues with employment, relationships, and independence tends to isolate people with Asperger's from their neurotypical peers.

Well, I would change the question. It's not so much what we would like them to know. It would be how do we get them to know things in the first place? There's a lot of coverage of children with Asperger's, but there's very little coverage in the news media of adults with Asperger's, so I think that's the real question. (Walter)

Children with Asperger's Syndrome transition into adulthood with Asperger's Syndrome. They will face the same and additional challenges in their adult lives. For Walter, better media

regarding Asperger's Syndrome, especially adults with Asperger's Syndrome, would increase the understanding of it.

Each participant expresses what she/he wants people to know about the experience of living with Asperger's Syndrome. Each person communicates his or her challenges and the way he or she navigates the world. What seems to stand out is the importance of the general population's understanding that their style of communicating may not be neurotypical, but it makes sense to them. They want future interactions to be amicable and a mutual experience for all.

### *Just Being Me*

Like everyone else, people with Asperger's Syndrome have individual identities. Each person will perform tasks in a manner that is comfortable for him or her. Although they want to fit in with their neurotypical peers, maintaining self is important. Each person wants to be accepted as an individual, not a disability. Often, being observed as a disability first opens the door for many stereotypes to be made when people do not understand or get to know a person first. Most importantly, they do not want anyone to make new policies, or behave differently while in their presence. They want Neurotypicals to understand that this is how they navigate the world.

Arthur addresses one assumption that people have about the organization skills of people with Asperger's Syndrome. He shares how he deals with the challenge.

Personally is – multi-tasking is always a – always a problem. I hear that that's a problem for everyone, but, you know, if I'm doing something, I focus on it. Don't expect me to be paying attention to this and that at the same time. It's just not going to happen. I can't influence my work when I've got half a dozen different contracts that I work on all at the same time. And I have to make a sheet for myself, listing where I am on each one, or I am going to forget and then they're going to get all out of order. (Arthur)

Arthur considers himself a goal-oriented person and recognizes that attempting more than one task at a time is a challenge. He developed a system for the workplace that keeps him organized and his work done in a timely manner.

Robert speaks about the expectations that people have of people with Asperger's Syndrome who are successful in a particular area. For some reason, people expect perfection in all facets of your life.

Well this probably is the toughest thing with me is just what I call the "therefore" factor. Ok and "you were successful in this area therefore...." And that "therefore" is almost always wrong. "Therefore you should be able to you know understand what I'm saying." "Therefore you should be you know able to better communicate." "Therefore you shouldn't have a problem going to Wal-Mart. What do you mean it's too noisy?" You know. I mean therefore we're constantly being shoved into these "therefore" cubbyholes that we don't fit in. So don't think – I mean yeah we can be extremely successful in a certain area. Which is particularly our area of interest, our area of focus. But that doesn't always translate to other areas like it does for other people. (Robert)

People assume that everyone is equal in their way of being. Robert does not want to be measured based on others' perceptions of how he should think, be, or function in life. He feels that everyone has strengths and weaknesses.

Shirley considers herself a nice, kind, and polite person. She desires to develop and maintain relationships with others in the community.

So when I think about getting in, like, a social skills training, or social skills class. One guy was telling me I could go to Toastmasters.

She thinks that improving her social skills will help her build relationships. She is currently researching groups that provide social skills training to support her through life transitions.

Walter identifies with others with whom he has developed and maintained a relationship over the years. He found a circle where everyone is accepting of one another. Walter reveals what it is like being himself.

Well I've got a small network of friends. I just last night, as a matter of fact, prepared dinner for several of them, and I'm grateful to be in touch. And also I kept in touch with a few friends from college. So I suppose it's like any person having a network of friends, except mine would be smaller and it's very close. I don't know if it's closer than others, but it's a small, close network of friends. (Walter)

Walter maintains a close relationship with his friends. For him, numbers of friends are not as important as the time they spend together. He appreciates their friendship and feels comfortable just being himself.

Arthur, Robert, Shirley, and Walter addressed the question, “What is the lived experience of having Asperger’s Syndrome?” They shared who they are and how they have navigated the neurotypical world from childhood to the present. These participants have wandered through many social mazes of society during their lifespan. They faced many challenges in school, on the job, and the community.

In this chapter, I have attempted to capture the lived experience of these five adults with Asperger’s Syndrome as they search for place in a neurotypical society. They offered a personal account of how they navigate the world. Each person had both similar and different experiences living with Asperger’s. They provided a first-hand experience of their challenges as well as successes in school, employment, social life and the community in their effort to fit into the neurotypical society. They strived to be more than an invisible face in the crowd. At times, their paths collided with Neurotypicals, yet they developed strategies to fit in as a way to be near and visible in a place that they share. They voiced what people should know about Asperger’s Syndrome to increase awareness. In addition, they hope to dispel the myths often associated with the syndrome in order to increase a better understanding and demolish the wall that has created an outsider status for so long. How might people with Asperger’s Syndrome be authentic without losing their self in the process when in the presence of others? Each participant attempts to contribute to society as a person, rather than a person with Asperger’s Syndrome. When necessary, they willingly use scripts as a way to fit in.

How can schools and families support students with Asperger’s Syndrome to assist in a smooth transition from school to adulthood to find place in the community? What strategies can teachers use to include these students in more school related social activities? There needs to be greater awareness in schools, work environments, and the community. What can be done to assist people with Asperger’s Syndrome to demonstrate their skills to employers and maintain tenure on the job? In Chapter Five, I discuss the pedagogical insights and recommendations for

addressing ways in which school and work can be changed to enhance the lives of Aspies. I also provide recommendations for further research.

## CHAPTER FIVE:

### BUILDING NEARNESS TO PLACE IN A NEUROTYPICAL LIVED-WORLD

Do not judge your neighbor until you walk two moons in his moccasins.

(Cheyenne Proverb) [www.oneproverb.net/bwfolder/nativebw.html](http://www.oneproverb.net/bwfolder/nativebw.html)

This Cheyenne Proverb speaks to judging another person before getting to know or understand his or her circumstances, which requires putting one's self in another person's place. When I reflect on the experiences encountered by the participants during their lives, this proverb comes to mind. People with Asperger's Syndrome are often judged on how they navigate the world. Although their way of being makes sense to them, sometimes their way may be unacceptable to others. In this study, I have been given a unique opportunity to share their experiences and to walk in their shoes.

Van Manen (2003) believes that "To present research by way of reflective text is not to present findings, but to do a reading (as a poet would) of a text that shows what it teaches. One must meet with it, go through, encounter it, suffer it, consume it and, as well, be consumed by it" (p. 153). Through the investigation and writing process, I was able to explore, ponder, internalize, echo, and reflect on the lived experiences of the participants. These steps guided me in bringing the phenomenon to light.

As an educator who assists students with their transition from school to adulthood, I have observed how students with Asperger's Syndrome search to find place among their neurotypical peers. Van Manen (2003) writes that phenomenology asks, "What is this or that kind of experience like?" (p. 9). Their desire to find place brought me to ask the question, "What is the lived experience of individuals with Asperger's Syndrome?" To answer this question, five adults with Asperger Syndrome have come forward to share their experience of living with the syndrome. Their experiences resonate with the research regarding bullying, peers, personal relationships, and employment.

In Chapter Five, I open up the lived experiences of individuals with Asperger's Syndrome from childhood to adulthood, beginning with sharing their feelings of receiving the diagnosis and putting a name on the unknown—Asperger's Syndrome. Arthur, George, Robert, Shirley, and Walter open up the phenomenon through their experiences at school, at work, in

personal relationships, and in the community. The participants share their childhood experiences and interactions with peers during their early school years. Often, they were a target for bullies in school. Yet, they continued to search for a good fit. As young adults and adults they brave the social roller coasters and mazes of the neurotypical world. Many times, the participants indicated that they felt like a foreigner in their own community. It is my hope that the lived-experiences of the participants will offer insight into how people with Asperger's Syndrome find place in what they call a neurotypical society and what we as educators might do to help them prepare for and be received in this place.

Individuals with Asperger's Syndrome want to develop a nearness to others with whom they live among in the community. What is nearness? Heidegger (1971) states, "Nearness, it seems, cannot be encountered directly. We succeed in reaching it rather by attending to what is near" (p. 164). What is near are people with Asperger's Syndrome who attempt to be with their neurotypical fellow human beings. Like Neurotypicals, Aspies seek presence in the community. They are reaching to attend to those near to them. What does it mean to reach? According to the *Merriam-Webster Online Dictionary (2008)*, 'reach' comes from the Middle English word *rechen*, meaning, "to stretch out." People with Asperger's Syndrome often stretch themselves in their attempt fit into the crowd.

Although challenged by communication and social interactions, the participants do make an effort to fit in. They acknowledge that people may not observe them as being normal. What is normal? According to the *Webster's Unabridged Dictionary of the English Language (2001)*, the word 'normal' comes from the Latin word *normalis*, meaning, "conforming to the standard or common type; usual; not abnormal" (p. 1321). To them, normal is being a part of an inner circle. Throughout their lifespan, Aspies have been familiar with the outsider's circle. Their mission is the inner circle, which has been an arduous task.

Through my journey with the participants I have gained a tremendous insight into the lived experiences of individuals with Asperger's Syndrome. Often, their way of being in the world is misunderstood by others and creates distance rather than nearness. Through this phenomenological study, I share how schools, employers, and the community can support individuals with Asperger's Syndrome so they may become active participants in society. Recommendations are offered to help bring about a better understanding and awareness of the

contributions and needs of individuals with Asperger's Syndrome, as well as suggestions for future research.

### Negotiating Place in Life's Social Maze

People with Asperger's Syndrome often find themselves negotiating the social maze that many others take for granted daily. Thus, the social interactions that others engage in on a daily basis are desired by many individuals with Asperger's Syndrome. Barnhill (2007) elaborates, "Building social relationships by making friends and establishing intimate partners is a key developmental life stage for young adults. This is another area of significant challenge for many people with AS. Although they report a desire for relationships, they tend either to approach others in an inappropriate physical or verbal manner or to misread subtle social cues or body language" (p. 121). These interactions seem to create a feeling of awkwardness for people with Asperger's Syndrome.

#### *Fitting into Place*

Finding one's place in society is important. Everyone needs a place to call home. People with Asperger's Syndrome search through family, friends, organizations and other social outlets for ways to fit. Family provides unconditional love, and a person will always have a place within the family unit. However, fitting into a place that is outside the family makes a person feel accepted and part of a social circle that they developed. It is not a forced relationship, but one that develops mutually over time. These relationships become an extension of the family. This social circle opens up new experiences and support networks. The participants reveal their experiences of finding and fitting into place. Robert met his wife at a church sponsored club. Shirley plays the piano for her church. Walter gets together with a circle of friends to enjoy social events. George uses an online social network. Arthur enjoys canoeing, hiking, and martial arts. The participants found a place to fit in. Through their social activities, they found presence among others in the crowd.

#### *Being Present*

What does it mean to be present? According to the *Webster's Unabridged Dictionary of the English Language* (2001), 'present' comes from the Latin word *praesent*, meaning, "to come to show (oneself) before a person, in or at a place" (p. 1529). The participants bring attention to

their way of navigating the world to those who may not understand or have awareness of their way of being with others. Meeting the social demands continues to be a barrier for people with Asperger's Syndrome. Although meeting social demands is an expectation in many milieus in our society, people with Asperger's Syndrome may not conform to those demands in the same manner as their neurotypical peers; however, their experiences demonstrate that they make an attempt. That attempt requires much energy and often proves to be quite a laborious endeavor. Nevertheless, they take steps to be near and actively resemble their neurotypical peers at school, the work environment, and the community. People with Asperger's Syndrome do not want to be clones. According to the *Webster's Unabridged Dictionary of the English Language* (2001), 'clone' comes from the Greek word *klōn* meaning, "a person or thing that duplicates, imitates, or closely resembles another in appearance, function, performance, or style" (p. 388). They want to be with others while maintaining their own identities as individuals.

Heidegger (1962) emphasizes, "Awareness in the broader sense lets what is ready-to-hand and what is present-at-hand be encountered 'bodily' in themselves with regard to the way they look. Letting them be thus encountered is grounded in a Present" (p. 397). People with Asperger's Syndrome are bodily present in the world in which we live. Yet, they continue to struggle in social settings. Aspies' social awkwardness are demonstrated through their approaches to others with whom they come into contact in a social setting. Often, Aspies' approach to others in a social setting may be perceived as overbearing to a stranger. Often, this lack of social awareness creates misunderstandings and halts the conversation or social connection. Once again, the circle breaks and the person with Asperger's Syndrome stands alone waiting for the others to return.

People with Asperger's Syndrome have talents and abilities like their neurotypical peers and want to be present in the sense of the contributions they make to society. They survived the transitions of their early school years as well as the unpleasant experiences of attempting to fit in with their neurotypical classmates. When Aspies attend their class reunion or happen upon a classmate in adulthood, they want to be identified as a former classmate, not as the student whom everyone bullied.

## *The Schoolhouse and Beyond*

Increasing awareness is important in helping people understand the challenges of students with Asperger's Syndrome. Arthur, George, Robert, Shirley, and Walter share school experiences and the type of supports that would have helped them to be successful at school. George states that teachers need to be aware of students with Asperger's Syndrome. Often, peers misunderstand students with Asperger's Syndrome which may open the door for students with Asperger's Syndrome to be ridiculed and fall victim to their classmates' taunts and jeers. When teachers are familiar with the needs of students with Asperger's, they can provide a level of support and tolerance that set the tone for classmates to follow. In this way classmates can interact and work with those who have Asperger's Syndrome in a positive manner.

Van Manen (2003) notes, "Pedagogy inheres in our phenomenological response to the child's natural helplessness" (p. 146). Counselors and teachers may not be as familiar with the needs of students with Asperger's Syndrome to provide both academic and social support. Walter believes, "They can offer encouragement. They can keep in touch with the student's teachers to explain to the student's teachers the social problems, the intellectual problems that—problems of concentration that students with Asperger's have." It appears that Walter did not feel connected with his teachers and classmates. He would have desired a liaison person to provide support during his school years. He believes that a support person would have made a difference in the way he and his classmates interacted with each other. Teachers and counselors who understand the learning styles and social issues that students with Asperger's Syndrome encounter at school can offer support to staff to resolve issues that hinder success in the classroom. School staff can help guide students with Asperger's Syndrome toward a smoother transition from school to adulthood.

All I can say is just understand—which is kind of—it's not just Asperger's. It's even a lot of Neurotypicals. As far as the neurotypical students go, just understand that different people learn in different ways. (Robert)

Robert wants schools to acknowledge that all students vary in the way they learn. Every learner does not fit into the same box. Various learning modalities need to be explored and implemented when teaching skills to students. Teachers cannot assume that all students fit into one particular style of learning. Attwood (1998) notes, "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 precious or original abilities using an unconventional strategy. The child appears to have a different way of thinking and problem solving" (p. 120). Robert wants educators to understand and use a variety of strategies with students. Therefore, according to Robert, all students will benefit. Arthur looks at another need of learners. He suggests:

...a way to do that is to think about the curriculum itself in that a lot of times school is where you go, and you sit down, shut up, do your work for however long, and that doesn't necessarily encourage—end in thoughts or creativity, but it should be more to teach not the what but the how.

That way you can apply that knowledge to whatever subject you're studying, but that's rather broad. It's not something that just helps people with Asperger's. That would help everyone. (Arthur)

Arthur looks at the typical classroom expectations of a learner. He knows that the curriculum is designed to deliver information for students to retain. Aspies are not traditional students, and they may challenge the design of the curriculum, instruction, and teaching strategies. He gives the scenario, "If you're dealing with a class on the American Revolution, for example, it's not enough just to say, well, there was this battle that was fought at Lexington after the British occupied Boston. Okay, well and good, that tells me what happened. It didn't tell me why it happened and it didn't tell me why people who were participating in these events did what they did." Arthur wants teachers to use a variety of teaching styles to reach all students. Students who enter the classroom, take their seat, read the board for assignments, work quietly and do not ask questions respond differently than Aspies. Each student comes with a different point of reference, and different level of skills for learning and retaining information.

Robert had similar classroom experiences. He says, "Topics like what is a computer, and what is the history of computers, and all this kind of stuff, and the teacher—every test was a 50 question true/false test. And I'd read these questions, and with my experience, the answer to every single one of them was, it depends." When questioned, Robert stood by his choice by justifying his answers and eventually got the credit. Attwood (2007) affirms, "One of the learning-profile characteristics associated with Asperger's syndrome is a strong drive to seek

certainty, and the child or adult appears uncomfortable with any situation in which there is more than one right answer” (p. 241). Robert’s action supports this theory. Students with Asperger’s Syndrome need to understand ‘why’ when learning new information. Teachers can act pedagogically by providing students with more than the basic information and providing many opportunities for students to use various learning styles to demonstrate their academic ability in the classroom.

The participants move from the schoolhouse to the community. Some of the issues that challenged students with Asperger’s Syndrome during the school years tend to follow them into adulthood. They put forth their best efforts to blend into the crowd like their neurotypical peers. Yet, there is a fear that they will not fit in.

### Living up to the Crowd

If you look within a crowd of people, you will instantly observe diversity. Everyone may wear the same red shirt, but hair colors, skin hues, sizes, height, and eye colors will be different. Although the attire of the crowd may be a red shirt, their differences go beyond the outer garments. A common interest makes them one. As the spotlight shines across the crowd, people with Asperger’s Syndrome who share the same interest as their neurotypical peers are claimed by fear. So, what is their fear? The fear is that others may see that their shirts are a different shade of red, that someone may tell them that they do not belong with this group. Yet, their presence screams, “I am here and I belong.” People with Asperger’s Syndrome desire membership in the neurotypical world while maintaining their identity.

Everyone wants to fit into a circle. However, doing so may mean that one has to conform to the expectations of the circle. The participants use various strategies to move from the outside to inside various circles. Yet, getting inside a circle continues to be a challenge. Arthur asserts:

If I had the ability to plug into that wavelength that everyone else is on, I could understand people in the world around me the way that everyone else does—not necessarily out of a desire for conformity, more out of a desire so that I could understand and actually open up the glass door and be on the right side of it instead of always looking in. (Arthur)

Arthur acknowledges his desire to fit into the group around him. Like everyone else, he wants to be an insider. Insider status brings a person near to others with whom they desire to connect and seek visibility. Page is an adult with Asperger's Syndrome. He gained an understanding of connecting with others by reading Emily Post's book on *Etiquette*. Page says, "It suggested ways to inaugurate conversations without launching into a lecture, reminded me of the importance of listening as well as speaking, and convinced me that manners, properly understood, existed to make other people feel comfortable, rather than (as I had suspected) to demonstrate the practitioner's social superiority" (Page, 2007, p. 40). Thus, by turning to good conversational etiquette, Page learned to engage in a two-way conversation. Walter mentions that he learned to listen to others. Becoming a listener moves him closer to his neurotypical colleagues.

### *Living Behind a Mask!*

Some of the participants spoke about wearing a mask as a way to blend into the crowd. It is astounding to know that a person feels compelled to mask his or her uniqueness to fit in. This seems to be a great personal sacrifice to make for the sake of being in the company of others. However, for these Aspies, wearing a mask has moved them closer to the social inner circle. After conversing and spending time with the participants, I had the opportunity to reflect on what it must be like to live behind a mask in both personal and professional settings. Honestly, Neurotypicals wear masks at times. We may wear masks at work and in social settings. Nonetheless, Neurotypicals may appear to wear a mask without some of the challenges that Aspies encounter.

The participants discovered useful strategies that allow them to take their place in society. In Chapter Two, some of the research spoke to people with Asperger's Syndrome being themselves and wearing no mask. While this maybe true for some, I found that in my conversations with the five participants, they do wear masks as a way to blend into the neurotypical world. These adults tried being themselves in their youth, but it appears that wearing masks brought them closer to the neurotypical world. They are like a chameleon, blending into the environment when necessary.

## *Finding Balance Between the Aspie and the Neuro Worlds*

How does one find balance in society? Our society is rich in diversity of people, skills and abilities. Yet, I talk about two worlds. One world is that of Aspies, and the other world is that of Neurotypicals. Nonetheless, we live in one society, which is large enough for both groups to exist as one. What divides us seems to be a lack of understanding of how each group navigates the world. The participants in this study are individuals with Asperger's Syndrome who often find themselves standing on the outside of the neurotypical circle. In order to find place, he or she must act. Arthur says:

I can act neurotypical. I can't be neurotypical. And for day-to-day, that's good enough.  
(Arthur)

Arthur shares that he willingly plays the neurotypical game to get through his daily routine. Over the years, Arthur has learned that while being himself is important, he is often misunderstood. Therefore, acting is his way of finding balance in the neurotypical world. Arthur has chosen to accept this role to gain the visibility he desires.

Each fingerprint on every human being is different. Imagine four billion people now present in the world, plus all those who come before and will come in the future. All have their own unique fingerprints. There are no duplicates. How could anyone think up so many variations? That really boggles my mind. And yet, it is an indisputable fact. Each one of us is different. (Satir, 1978, p. 9)

Satir explores the uniqueness of people through the one thing that makes us different from others, our fingerprints. Our fingerprints mark our unique identity from that of our parents, siblings, and every person in the world. This uniqueness serves the purpose of making each person an individual.

Individuals come together to form a group in society. Yet, a person may be included or excluded from the group based on characteristic such as, but not limited to, ethnicity, gender, socioeconomic status, political affiliation, religious beliefs, or ableism. The participants feel they are excluded for reasons relating to behavioral norms inherent in their way of being. Their lived-experiences demonstrate their willingness to put forth a great effort to interact with and be a part

of the community. They admit to going the extra mile to have a social outlet that is comfortable for them.

Their voluntary participation in this study is evident that they want to find a balance between their world and the neurotypical world. By sharing their lived experiences they want to bring awareness to and a better understanding of people living with Asperger's Syndrome. To them, awareness stands between the insider status of the neuros' world and outsider status of people with Asperger's Syndrome. Walter suggests that more media attention geared toward the problems of adults living with Asperger's Syndrome would help to blend the two worlds.

### Living in a Boxed Society

The only way by which any one divests himself of his natural liberty and puts on the bonds of civil society is by agreeing with other men to join and unite into a community. (Locke, 1824, p. 186)

Locke's quote articulates a call for people to unite as a community. We live in a box called society. This box consists of many communities. Often, communities pride themselves on a population rich with culture and diversity. Yet, communities may not accept diversity when it does not fit into a prescribed set of expectations. It is difficult to live in a box when individuality is not accepted.

### *The Unique Self*

My journey into the world of Asperger's Syndrome provided me an opportunity to witness the genuineness of the participants. As I spent time with each person, I learned about his or her likes, dislikes, accomplishments, challenges, and humor. Often, their way of being is challenged by others since it does not conform to the norm of the mainstream. The participants, like their neurotypical peers, set goals for themselves and attempt to make those goals a reality. Their approach to accomplishing goals brings them closer to actualization of those possibilities. MacLeod and Johnston (2007) share, "Despite the fact that many individuals with Asperger Syndrome possess both the potential and the aspirations to conform to societal demands, the majority continue to experience significant social exclusion in their daily lives" (p. 87). People with Asperger's Syndrome are misunderstood in social circles due to their inability to read the body language or social cues of a person. Roe (1999) notes, "You could inadvertently insult

someone, or even get that evil response from the listener: subtlety. They pretend to accept what you say, but really are only bewildered, confused, or awestricken if your comment seems bizarre” (p. 252). When an Aspie shares a special interest or makes a comment to a person, they are unaware of the other person’s body saying “enough”. Some people may perceive an Aspie as arrogant. These unintentional moments can lead to exclusion and avoidance by others in future encounters.

Some of the participants displayed humor as they shared life experiences. In some cases, those experiences made me sad, and at times, some of those experiences were overwhelmingly powerful to hear. However, I was able to reflect on their experience in order to reach new insights. I found that maintaining one’s self takes efficacy in order to stand tall among giants.

### *Being Self in Community*

What does it mean to be a community? It means that everyone is acknowledged for the diversity he or she brings to the community. Some neighbors may perceive a person with Asperger’s Syndrome living on the same street as a recluse. They may have little or no contact with the person with Asperger’s during their year in the community. The neighbor with Asperger’s becomes a superficial member within that community. Again, they are on the outside looking in. Morrison and Blackburn (2008) acknowledge that “The well-established importance of being a member of a community provides individuals opportunities for sharing information, gaining knowledge, developing relationships, and problem solving” (p. 5). It is impossible for a person with Asperger’s Syndrome to share information and develop relationships when there is no one around to practice those social graces required in social society. Many times, people with Asperger’s Syndrome attempt to be one with the community, but are ignored due to their way of navigating the social maze. Roe (1999) believes, “It is really difficult to get across to many people without AS the terrifying feeling that results from social skills deficits. It is also difficult for most people to understand just how much of their success in life depends on good handling of social situations” (p. 252). Building a bridge to community takes more than just being in a room with others. It requires getting to know the person and help them navigate the social mazes one at a time. To build community means that diversity is welcomed and celebrated by all. People can come as they are without the fear of raising eyebrows. It is important to help a person with Asperger’s Syndrome know the social cues in a tactful manner. Ignoring their presence will not

bring them near to others if they are not aware of social blunders. Knowing what the social climate is like beforehand can assist not only people with Asperger's Syndrome, but any newcomers to the circle.

Self-trust is the first secret of success, the belief that if you are here the authorities of the universe put you here, and for cause, or with some task strictly appointed you in your constitution, and so long as you work at that you are well and successful. (Emerson, 1904, p. 155)

Emerson's expression on self-trust is a reminder that everyone can achieve success. It is an attainable goal that takes work. How does a person with Asperger's Syndrome successfully maintain self in the community? Maintaining self means persons must trust in their abilities and talents to contribute to the community. Success becomes a reality when Aspies and Neurotypicals come together and accept one another for the abilities and talents they possess. Also, it is important to understand that everyone has flaws. Being a member of the community means working together to help each other and build a strong bond. Usually, that bond is put to the test when an emergency occurs in the neighborhood. Neighbors come together to assist those in need like a family unit. The participants took the first step in reaching success when they agreed to share their experiences of having Asperger's Syndrome. The five participants in this study convey a proactive voice through their lived-experiences. This is an important step in building understanding and gaining full membership in the community.

### Journeying into the World of Asperger's Syndrome

I began this journey of addressing the lived experience of people with Asperger's Syndrome with my own experience as a Special Education Teacher, fighting for decent books for my students. My commitment of working with students with disabilities came with a price. When I met Mark, a young man with Asperger's Syndrome whose way of being caused others to treat him as if he were invisible, I was called to explore his world.

People with Asperger's Syndrome are usually average to above average in intelligence, yet often lack social graces. The general population may not understand or recognize the characteristics of an individual with Asperger's Syndrome, thus feeling that they should be able to conform to acceptable behaviors like everyone else. Tolerance curtails when intelligence is

included in the equation. It is a difficult place, especially when others only see intelligence and not the person.

My phenomenological research asks the questions: “What is the lived-experience of individuals with Asperger’s Syndrome?” I stayed with this question, even though it was difficult to pursue, and often my peers were uncomfortable discussing what I was discovering. I recognize that this study is important in order to increase understanding and awareness of people living with Asperger’s Syndrome. At times, the journey was lonely and very tiring. Yet, I was determined and remained focused on my commitment to learn more about individuals with Asperger’s Syndrome. Since my journey began, I observed the challenges that students and young adults with Asperger’s Syndrome encountered during their transitions years. Those challenges spill over into their adult life.

These now young adults are unable to achieve a level of independence in the community. Often, entry-level employment is short-lived with little opportunity for benefits or advancement. One week I received a call from a student requesting permission to use me as a reference (This is a rule I teach to all students). A few months later, I received a call from the same student informing me that he quit or was let go (never fired). This is disheartening experience for anyone to bear.

As an educator, I have changed the way I work with students who have Asperger’s Syndrome, as well as other students with disabilities. First, I make it a point to work with students during the first week they enter high school. I meet students to get a sense of their career and life goals. Second, I introduce myself to the family and share the type of transition services their child is entitled to receive to strengthen their transition from school to life. Many times, families will tell me that their child is too young and they have plenty of time to receive my services. However, my research participants have taught me that their high school experience is a significant factor in making a smooth and successful transition into the challenges of adulthood. When families share concern about their child’s social deficits and the future, I stress the importance of practice and work readiness. I share information about a work readiness class that provides practice in employment and social skills within the community. Often, it is a hard sell, and some families still do not see the benefits of the class.

My experience with Aspies has taught me to play up their strengths while building the areas of need. For example, many people with Asperger's Syndrome are comfortable with a routine. I have found that Aspies need as much information about a new environment or change in plan as possible. They do not like going into a situation cold. If an Aspie is scheduled for a career assessment, my experiences have taught me to provide as much information about the people and environment as possible. Then I introduce the student to everyone involved in the center before the scheduled day. This reduces the anxiety they may feel when change interrupts their routine. Sometimes, this process is not possible to do, but it is important to make them as comfortable as possible. Building a trusting relationship with students who have Asperger's Syndrome is the first step in their transition. They depend on people they trust. If you are not available, they will wait. You have to follow through on what you tell them you will do, or they will remind you. Students with Asperger's educated me to observe the situation. In addition, when you are in doubt, do not assume, and just ask the questions.

### *Seeing Place Through the Eyes of Aspies*

When I began this journey into the world of people who have Asperger's Syndrome, I wanted to know what the experience was like for individuals who lived with the disorder daily. I wanted to hear what place means in their voice. When the five participants were young, Asperger's Syndrome had not been introduced in the United States. Therefore, the Asperger's Syndrome was not included under the Education of All Handicapped Children Act of 1975 or the *Diagnostic Statistical Manual of Mental Disorders*.

It is important for educators to know how to support students with Asperger's Syndrome. The challenges and needs faced by those living with the syndrome require an understanding of how to provide support as they transition through school. Support is important for all students. However, it is extremely important for students with Asperger's Syndrome during the school years to have practice in both communication and social interactions with their peers and adults. The participants pointed out that small talk was an issue on the job. In school, students with Asperger's Syndrome can participate in group projects. Schools can provide practice for students with Asperger's Syndrome through social interactions with peers in a variety of school related activities. For example, schools have sponsored organizations that students may be eligible to join. The yearbook, school newspaper, chess, athletics activities are just a few of the activities

that students can participate in during the school years. Stanley and Karen, mentioned in Chapter One, participated in school sponsored organizations. Stanley was a member of the chess club and Karen participated in a music ensemble. Both students were talented in their chosen areas. They took the steps to join these organizations. These students found a place to fit into the school social circles.

One way of knowing how to assist people with Asperger's Syndrome is seeing through their eyes. How does one see through the eyes of another person? Seeing through the eyes of someone else requires you to put yourself in that person's place. I think about strategies that people use to cope with various situations in their life. They have used these strategies in the past and these strategies make sense to them. I think about strategies that I use and make sense to me. For example, when I know that a situation may cause anxiety for a student, I make sure that the student is comfortable by answering as many questions as needed to make them feel at ease. I have learned that every question is an important one when it affects the life of someone else. Although this can be difficult for some to do, it is necessary in order to make sense of something. The participants put you in their shoes. Students can help their classmates by practicing tolerance in the classroom and in the cafeteria. Being a new student at school can create an uncomfortable feeling. There are new rules to follow, names to learn, and classes to find. The biggest hurdle may be surviving the lunch period. For example, the cafeteria can be an uncomfortable place for some students. The large crowd and noise level is especially challenging to students with Asperger's Syndrome. Some students with Asperger's Syndrome will forego lunch and head to the quiet space of the library or a teacher's classroom. Students can put themselves in another student's shoes by remembering their experiences in the classroom or cafeteria when they entered high school.

### *Accessing Place*

Place is wherever a person may be. Of course, place may mean something different to each individual. For individuals with Asperger's Syndrome, place means fitting into the social circle of society. They want to gain access to the inner circle and drop their outsider status. Gaining access to place means that people with Asperger's Syndrome will be able to share the inner circle with their neurotypical peers.

The significance of the study is to raise awareness of how people with Asperger's Syndrome navigate the world. Awareness is important since people with Asperger's Syndrome are often outsiders when it comes to social circles. The participants have developed strategies that help them fit in with their neurotypical peers. Over the years, they learned to how to play the neurotypical game. When some students with Asperger's Syndrome enter high school, they may continue to perform certain rituals in class, the cafeteria, and the hallways. These students can become a form of entertainment for their neurotypical peers. This type of visibility does not move students closer to the social circle.

In their quest to belong, the participants developed a strategy of using scripts as a way to resemble their neurotypical peers. Some may view this strategy as not being authentic. However, when people with Asperger's Syndrome present themselves authentically, they become translucent. Being translucent means that although a person with Asperger's Syndrome may be in the same space as Neurotypicals, their presence may not be acknowledged. They have been socially challenged for most of their lives and desire visibility among their peers. How does a person gain visibility? The desire to belong is strong, so people with Asperger's Syndrome do what works for them to fit in. Using a script gives Aspies visibility among Neurotypicals. They become a part of the circle. They become visible.

Portway and Johnson (2005) speak about the risks of having a non-obvious disability such as Asperger's Syndrome. They share, "Everyday subjectivity felt risks include misunderstanding implicit meanings and social rules, unusual sensitivity (heightened or lessened) to certain sounds, smells and to the pain of others, feeling disproportionately distressed when a routine is broken or at an unexpected event. Everyday risks arising from the perception of others include being misunderstood, ridiculed, teased, exploited and ostracized" (p. 74). People with Asperger's Syndrome want to fit in but are challenged by the complications of the disorder. First, Asperger's Syndrome is not visible like some disabilities. For example, disabilities that are visible like visual, hearing, or mobility impairments require no explanation. Usually, people practice tolerance when interacting with people having these kinds of disabilities. However, Asperger's Syndrome can be quite puzzling to people, and it requires much more of an explanation. After all, people with Asperger's Syndrome may look the same as everyone else, but others may perceive them odd. Often, this creates misunderstanding and

isolation when an Aspie does not meet the social requirements of a group. They become socially absent within the group. Yet, when people with Asperger's Syndrome use scripts, it is not being inauthentic; it is how they access place with Neurotypicals in social settings.

Each participant wants to be near and shares that it is important to build nearness. This study reveals that three of the five participants with Asperger's Syndrome script their lives in order to fit into the neurotypical world. They have acquired great showmanship and can deliver an award winning performance when necessary. Although this is exhausting work, they continue to use scripts to be with others. The participants demonstrate how supportive they are of one another. They support each other through online networks, monthly meetings, and group social activities.

It is important for students, educators and employees to understand that like other citizens in society, people with Asperger's Syndrome want to have friends and be a friend. They want people to see their strengths and abilities. They want to contribute to the workforce. They want to enjoy the same leisure activities and be more active in social interactions.

A person's interaction with a person with Asperger's Syndrome can influence their visibility or invisibility among peers. Building friendships is an important part of our development as persons. Students with Asperger's have difficulty developing friendships. Sometimes, when Aspies reach out to their neurotypical peers for social interaction, they may not get a positive response. When those social interactions do not prove positive, they seek social networks among themselves. It is also important to understand that when people with Asperger's Syndrome are given opportunities to build support networks with their neurotypical peers, they can begin to enhance social awareness and find a seamless place in society.

#### Implications for Further Research

Striving for success is a lifelong commitment along an endless road on which we must keep our focus. We cannot make success a one-stop destination. It does not end with a few accomplishments. For example, my search of the literature on Asperger's Syndrome offered so much information about children with Asperger's Syndrome. Yet, little information was available on the lives of these children who grew up to become adults living with Asperger's Syndrome. To successfully understand the needs of adults living with Asperger's Syndrome, I

had to continue to research and travel the journey I had begun in search for information and answers.

My journey has taken me to five adults who were willing to share their stories. Conversations with the five participants reveal the areas for pedagogical practice that would be most important to address: families' involvement, early diagnosis, schools and community experiences, employment supports, and building meaningful relationships.

Families are the first social network for the child with Asperger's Syndrome. It is important to introduce children to social experiences early. It is imperative to provide experiences in grocery stores, restaurants, entertainment venues, places of worship, and the work environment as a volunteer. These are environments where people with Asperger's Syndrome will interact with their neurotypical peers. Although some families may express concern about certain social and work sites, experiencing various social and work environments can help their child to build appropriate social skills and learn to work through problems with others outside the family, such as supervisors, co-workers and the public. The early years serve as a dress rehearsal to practice social nuances. And since there are no designated lines for people with Asperger's Syndrome and Neurotypicals, everyone must stand in the same line with awareness that each venue will become a staple during adulthood. Research that would investigate these areas would add an important contribution to the literature on Aspies.

Early diagnosis is the key. Literature strongly supports early diagnosis of any disability is key. Walter, one of the participants looks at it this way "It is critical that Asperger's Syndrome be identified as soon as possible in a young person. The earlier it's diagnosed and handled, I think the easier it is for the person to adjust. I don't want to say the easier the problem is to confront it, because I think that the problem has to be handled gently, and it probably isn't exactly the best word to describe. And I think school is important because of its social setting to tackle this challenge." Research that examines the effect of early diagnosis would be important to address.

Schools can better serve students with Asperger's Syndrome by providing various social and work experiences that allow students an opportunity to practice appropriate social interactions with peers and adults on a daily bases in the community. At the elementary and middle school levels, community experiences for students may be limited; however, at the

secondary level where students are preparing for transition into life after high school, the community experiences are an important part of their educational programs. By expanding the academic programs beyond the four walls of the school building, the community becomes a part of students' learning environment. The first step to successful transitioning to adulthood is providing as many experiences as possible for students with Asperger's Syndrome. Research that examines the ways in which these experiences contribute to their development is surely needed.

The participants made it clear that they were outsiders during their school years. They stood out among their peers and were often targets for bullies. One way to incorporate their presence among their neurotypical peers is to develop activities in the school, as well as the community, that will encourage both students with Asperger's Syndrome and their neurotypical peers to work together as a team. This can encourage each student to use his or her talents and abilities while learning from others. Also, working together can set the stage for peer modeling and mentoring. Most importantly, students can learn to exercise tolerance of others they learn and work with in a diverse society. Studying the effect of bullying that Aspies receive would greatly enhance this body of literature in general in order to help develop prevention programs.

If you're giving me oral instructions and it's more than one or two steps, by the time you get to, say, to step four, I've forgotten what step one was. (Arthur)

Arthur states that educators can best assist students with Asperger's Syndrome in the classroom by varying the way they deliver oral instructions. When teachers give too many instructions at one time, often students with disabilities, including Asperger's Syndrome, cannot follow all the steps to complete an assignment. This leads to students becoming frustrated and not completing their work. The teacher may assume that the student is deliberately not completing the assignment, when in fact the student has missed important information needed to accomplish the assignment. Students with Asperger's Syndrome may not ask the teacher for assistance. Instead, they may shut down or act out in class. Classroom pedagogy for Aspies is a wide open area that needs further study.

Employment and supports on the job are other significant areas requiring attention. Some individuals with Asperger's Syndrome will find employment and be very successful. Some individuals with Asperger's Syndrome may not retain employment after the probationary period. Their inability to communicate effectively with others or keep up with the workload is often the

problem. Many times, individuals with Asperger's Syndrome may not seek help when they do not understand the assignment, or if issues arise with their duties and responsibilities. Projects fall behind schedule; it becomes a race against deadlines; and frustrations mount in the worker and the employer. Often, deadlines are not met within the given timeframe, and the worker is unable to follow through on an assignment. The person may face the risk of termination from the job that he or she depends on to maintain independence.

A new employee may need additional supports when starting a new job. There are so many faces, tasks, and policies to learn. In a conversation with Walter, he indicates that employees can benefit from natural supports on the job.

The first question is whether the person with Asperger's is intellectually equipped to do the job. If that person is, if that person can do the job, then it's important that there be some sort of—for a large company, a large organization, a large government agency, there needs to be some sort of coaching. Maybe that could be arranged through an employment assistance program. (Walter)

McCauley (2007) explains, "Mentoring, however, is a valuable way to transfer knowledge, foster talent, and promote best practices. By pairing new hires, whether entry-level or experienced, with a veteran employee, companies can help workers get up to speed quickly and make immediate contributions to the firm" (p. 17). Providing mentors in companies can help new employees navigate the daily office routines and ensure longevity on the job. A mentor can groom a mentee in the office policies, expectations, and social graces of a company to enhance work productivity and tenure. Grandin & Duffy (2004) notes, "Mentors can help you learn important social and job skills" (p. 35). The literature and the participants recognize that these are the areas Aspies have difficulties with on the job. Mentors can assist people with Asperger's Syndrome work through the social awkwardness that they may feel in the office. Mentoring may increase job performance as well. Research on this mentoring process is another area needing attention.

Building meaningful relationships is a part of our normal life cycle. The participants spoke often of needing meaningful relationships in the family, at school, at work and in the community. They talk of being a team member and being able to contribute to the team. My years of experience as a teacher working with students, families, and employers strongly

supports that when individuals are engaged in meaningful relationships, they tend to be more involved in school activities, more successful employees, and are able to contribute more to their families and communities.

This study has just begun the journey to understand the needs of adults with Asperger's Syndrome to help them become successful. Walter, one of the participants, voiced that more attention is needed on adults with Asperger's Syndrome and the challenges for secondary students with Asperger's Syndrome do not end when they graduate from high school. Sometimes, those challenges can intensify in adults without ongoing supports. In order to attend to the research needs I have just identified, the following four areas could be fruitful starting points.

First, is teacher education and preparation. Generally, teacher education programs require prospective general education teachers to take only one introduction course in special education. This provides soon-to-be teachers with an overview of the many challenges that a student with special needs may experience in the classroom. Although these soon-to-be teachers are given a variety of tools to support a student with special needs to access the general education curriculum, one course is not enough. Since there are students with Asperger's Syndrome in most general education classes, there needs to be more education and training for all teachers to be able to assist these students.

The Individuals with Disabilities Education Act requires that transition begin at age 14 or younger. Some students may benefit from transition activities as early as sixth grade. The transition years are very important to the success of students with Asperger's Syndrome becoming independent and active in the workplace and the community. Therefore, a second area of further research is needed to focus on whether or to what extent students with Asperger's Syndrome would benefit from implementing transition skills earlier than age 14 or at the secondary level.

My third recommendation deals with employers. Current research indicates that employers want a diversified workforce that includes individuals with disabilities. Therefore, additional research is needed on identifying best practices employers use with employees to orient them to the workplace. Manuals are a great resource for employees to use, but new employees may retain employment if they have human support to successfully move beyond the

probationary period and further their career potential. The participants expressed that they were not always successful on the job due to their inability to read social cues, and their lack of understanding assignments. Sharing and educating employers on the best practices may attract or maintain a diverse workforce.

The fourth area for further research would address strategies that school personnel use to prepare students with Asperger's Syndrome to develop appropriate social networks. As we move through our daily routine, we encounter people from many lifestyles. Some of the participants shared that they wear a mask to fit into the social scene. Some people become members of our social network for life. Other people may become acquaintances with whom we interact from time-to-time. A person should not have to wear a mask to belong. Most importantly, no one should feel excluded from social venues based on their way of being.

People with Asperger's Syndrome want to be a part of the social circles in life. When meeting a person for the first time, one may take an opportunity to get to know the person to determine commonalities. This is a fair way to get to know the person. Some say, "First impressions are lasting." Sometimes, a first impression is all a person may get to be invited into a social circle. People with Asperger's Syndrome want to be inside the social circle; they would like a person to get to know them first, to determine commonalities that bring them into the circle of society. Then, they will come full circle and be in place in society.

This study has provided a valuable insight into the experiences of individuals with Asperger's Syndrome. When approached about the study, they felt that it was important to have their voices heard. They shared descriptive experiences about feelings of isolation and bullying during the school years, the challenges of employment, and maintaining relationships. Their experiences support the literature. Sharing their experience is the first step in opening the door for other people to gain a better understanding of what it is like for a person having Asperger's Syndrome.

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APPENDIX A  
LETTER TO CO-RESEARCHERS

Date:

Dear:

Thank you for your interest in my dissertation research on people with Asperger's Syndrome. I value the contribution that you can make to my study and I am excited about the possibility of your participation. The purpose of this letter is to reiterate some of the things we have already discussed and to request your signature on the participation-release form that you will find attached.

The research model I am using is one through which I am seeking descriptions of experiences that you encounter with others in both your personal and professional life. In this way, I hope to raise awareness for others to gain an understanding of people with Asperger's Syndrome.

Through your participation as a co-researcher, I hope to understand the essence of living with Asperger's Syndrome as it reveals itself in your experience. I am seeking vivid, accurate, and comprehensive portrayals of your experiences as well as thoughts, feelings, behaviors, situations, events, places, and people connected to these experiences.

I value your participation and thank you for the commitment of time, energy, and effort. If you have any further questions before signing the release form or if there is a problem with the date and time of scheduled meetings, I can be reached at 301-420-1144.

Thank you,

Annette Neal-Miles  
Researcher



APPENDIX C  
THANK YOU LETTER TO CO-RESEARCHERS

Date \_\_\_\_\_

Dear \_\_\_\_\_,

Thank you for meeting with me in an extended interview and sharing your experience. I appreciate your willingness to share your unique and personal thoughts, feelings, events, and situations of living with Asperger's Syndrome.

I have enclosed a transcript of your interview. Would you please review the entire document? Be sure to ask yourself if this interview has fully captured your experience of living with Asperger's Syndrome. After reviewing the transcript of the interview, you may realize that an important experience(s) was neglected. Please feel free to add comments, with the enclosed red pen, that would further elaborate your experience(s), or if you prefer we can arrange to meet again and tape record your additions or corrections. The way your story is told and heard is critical.

When you have reviewed the verbatim transcript and have had an opportunity to make changes and additions, please return the transcript in the stamped, addressed envelope.

I have greatly valued your participation in this research study and your willingness to share your experience. If you have any questions or concerns, do not hesitate to call me.

Sincerely,

Annette Neal-Miles  
Researcher  
301-420-1144

APPENDIX D  
PERMISSION TO REPRINT POEM

February 2, 2009

6114 Cabot Street  
District Heights, Maryland 20747

Dr. Tony Attwood  
PO Box 224  
Petrie Queensland 4502  
Australia

Dear Dr. Attwood:

I am completing a doctoral dissertation at Virginia Polytechnic Institute and State University entitled "Finding Place in a "Neurotypical" Society: A Phenomenological Study of Individuals with Asperger's Syndrome." Asperger's Syndrome is a neurological disorder that hinders a person's ability to communicate and socially interact with others. My study examines how a person with Asperger's Syndrome navigates through his or her daily routine.

The poem entitled, "My Greatest Fear is Myself" (by Woodhouse, cited in *Asperger's Syndrome*, 1998, pp. 160-161) resonates with the fear and challenges people with Asperger's Syndrome encounter in an attempt to fit into social settings. I would like your permission to reprint in my dissertation the following:

"My Greatest Fear is Myself"

The requested permission extends to any future revisions and editions of my dissertation, including non-exclusive world rights in all languages, and to the prospective publication of my dissertation by UMI Company. These rights will in no way restrict republication of the material in any other form by you or by others authorized by you. Your signing of this letter will also confirm that you own [or your company owns] the copyright to the above-described material.

If these arrangements meet with your approval, please sign this letter where indicated below and return it to me in the enclosed return envelope. Thank you very much.

Sincerely,

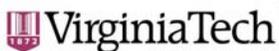
*Annette Neal-Miles*  
Annette Neal-Miles  
301-420-1144

PERMISSION GRANTED FOR THE  
USE REQUESTED ABOVE:

*A. V. Attwood*  
\_\_\_\_\_  
Tony Attwood

Date: *11/2/09*  
\_\_\_\_\_

APPENDIX E  
INSTITUTIONAL REVIEW BOARD PERMISSION



Office of Research Compliance  
Institutional Review Board  
1880 Pratt Drive (0497)  
Blacksburg, Virginia 24061  
540/231-4991 Fax: 540/231-0959  
E-mail: moored@vt.edu  
www.irb.vt.edu

FWA000005721 expires 7/20/07  
IRB # is IRB00000687

DATE: December 22, 2006

MEMORANDUM

TO: Marcie Boucouvalas  
Annette Neal-Miles

FROM: David M. Moore 

Approval date: 12/21/2006  
Continuing Review Due Date: 12/6/2007  
Expiration Date: 12/20/2007

SUBJECT: **IRB Expedited Approval:** "Finding Place in a "Neurotypical" Society: A Phenomenological Study of Individuals with Asperger's Syndrome" , IRB # 06-749

This memo is regarding the above-mentioned protocol. The proposed research is eligible for expedited review according to the specifications authorized by 45 CFR 46.110 and 21 CFR 56.110. As Chair of the Virginia Tech Institutional Review Board, I have granted approval to the study for a period of 12 months, effective December 21, 2006.

As an investigator of human subjects, your responsibilities include the following:

1. Report promptly proposed changes in previously approved human subject research activities to the IRB, including changes to your study forms, procedures and investigators, regardless of how minor. The proposed changes must not be initiated without IRB review and approval, except where necessary to eliminate apparent immediate hazards to the subjects.
2. Report promptly to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.
3. Report promptly to the IRB of the study's closing (i.e., data collecting and data analysis complete at Virginia Tech). If the study is to continue past the expiration date (listed above), investigators must submit a request for continuing review prior to the continuing review due date (listed above). It is the researcher's responsibility to obtain re-approval from the IRB before the study's expiration date.
4. If re-approval is not obtained (unless the study has been reported to the IRB as closed) prior to the expiration date, all activities involving human subjects and data analysis must cease immediately, except where necessary to eliminate apparent immediate hazards to the subjects.

**Important:**

If you are conducting **federally funded non-exempt research**, this approval letter must state that the IRB has compared the OSP grant application and IRB application and found the documents to be consistent. Otherwise, this approval letter is invalid for OSP to release funds. Visit our website at <http://www.irb.vt.edu/pages/newstudy.htm#OSP> for further information.

cc: File

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VIRGINIA POLYTECHNIC INSTITUTE UNIVERSITY AND STATE UNIVERSITY  
*An equal opportunity, affirmative action institution*