4-2009

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Richelle H. Kramer
St. Cloud State University

Recommended Citation

Kramer, Richelle H., "The Geek Syndrome… A Study of the Impact of Asperger's on the Family" (2009). *Culminating Projects in Social Work*. 14.
https://repository.stcloudstate.edu/msw_etds/14

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Richelle H. Kramer

THE GEEK SYNDROME..... A STUDY OF THE IMPACT OF ASPERGER'S SYNDROME ON THE FAMILY

by

Richelle H. Kramer

B.S., University of Iowa, Iowa City, 1988

A Thesis

Submitted to the Graduate Faculty

of

St. Cloud State University

in Partial Fulfillment of the Requirements

for the Degree

Master of Social Work

St. Cloud, Minnesota

April, 2009

This thesis submitted by Richelle H. Kramer in partial fulfillment of the requirements for the Degree of Master of Social Work at St. Cloud State University is hereby approved by the final evaluation committee.

Chairperson

Dennis Nunes

Dean

School of Graduate Studies

THE GEEK SYNDROME.... A STUDY OF THE IMPACT OF ASPERGER'S SYNDROME ON THE FAMILY

Richelle H. Kramer

The purpose of this study was to examine the impact of Asperger's Syndrome on the family. The study employed a qualitative research approach with a life story design. A purposeful sample of six families with children diagnosed with Asperger's Syndrome/Autism (AS) was used. In most cases, both parental caregivers of the identified biological or adopted children, consisting of five boys and one girl, were interviewed. The interview consisted of a free flowing conversation addressing the impact that Asperger's Syndrome has had on the family. The Care Giver Strain Tool was informally used as a guide to ensure all relevant subject areas of care giving were addressed.

Seven themes emerged. *Why Is Junior So Odd* focuses on the initial identifications that parents made when they realized that their child was developing differently from his/her peers. *What Kind of Help Should I Access and Where Do I Find It* found that as each family moved into the preschool years, they identified an increased need to seek out help and support. *This Is Not What I Expected* portrays how the families defined the impact that the AS child was playing on their family life script. *Relationships are Challenging* illustrates the complexities of relationships with extended family, friends, and the community. *Problems with Peers* describes the experiences that occur between the child and his/her peer group and how these issues affect the family system. *The School Experience* identifies the impact school plays on the family's functioning and stress levels. *It Is What It Is: Living with Atypical Behaviors* explains the adjustments that are made by the family and the efforts towards homeostasis that occur.

The results of the interviews suggest that these families share many of the same issues including stress, frustration, need for routine, challenges with the school, concerns about peer issues and bullying, relationship disputes, and concerns about the future. Implications for practice include education, community awareness, additional funding opportunities, and extensive and ongoing support services to families.

Implications for future research strategies include earlier identification, intervention, and training opportunities for all helping professionals and families.

April 09
Month Year

Approved by Research Committee:

Gary J. Whitford
Gary Whitford Chairperson

ACKNOWLEDGMENTS

To my husband, who has put up with my emotional and physical absence from our family for the last 2 years. His support has enabled me to see this process through.

To my almost adult daughter, Melyssa, of whom I am very proud.

To my son, Matthew, for teaching me about the beauty of the human spirit.

To my daughter, Meaghyn, who has understood that when Mommy is studying, lappy time must wait.

To my professors, for their support and encouragement.

To my work colleagues, for supporting me throughout this endeavor, you are a great group of people.

To my MSW cohort, my life is so much richer by knowing each of you.

To God, I often wonder why I have been handed so many challenges throughout my life. I may not understand why, but I have faith that the reason is good. With God's continued guidance and support (and a little Prozac), if I can leave this world a better place for the life of at least one child, I have been a success.

I want to share with you one of my favorite mother-son conversations. One day, we were chatting and I said to my son, “Matthew, do you know how many feet are in a yard?”

He thought about the question for a moment and answered, “Well, it depends on how big the yard is……”

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Chapter I

INTRODUCTION

The topic of this thesis is Asperger's Syndrome and its impact on the family. Asperger's Syndrome (AS) is a neurobiological disorder named after the Viennese physician, Hans Asperger (Kirby, 2007). Asperger named the disorder "autistic psychopathy" or "autistic personality disorder" in 1944 (Schnur, 2005).

The reason that I am interested in this subject is that I am the parent of a 16-year-old son with Asperger's Syndrome. This introduction will give the reader background on why further research into this topic is so very important for all individuals touched by Asperger's Syndrome, and especially for the family living with the disability every day.

Although described by Hans Asperger in 1944, his work went largely unnoticed. It was not until 1981, when Lorna Wing wrote her seminal paper on the syndrome, and named it after Asperger himself, that attention to the disorder grew (Robinson, 2007). Wing is also credited with spurring the birth of parent organizations, literature on autism for parents, and work towards the treatment of care and families of affected individuals (Wolff, 2004).

There is much speculation as to why Asperger's work went largely unnoticed. Two of the reasons follow: one is that Asperger's paper was only written in German (Volkmar et al., 2000). The second reason is that Asperger's work was largely overshadowed by the tumultuous times of World War II (Wolff, 2004).

Individuals affected by AS exhibit a wide variety of characteristics. Diagnostic criteria used for AS are frequently used inconsistently (Howlin, 2000). The disorder and its characteristics can range from mild to severe. Individuals with AS show marked deficiencies in social skills, have difficulties with transitions or changes, and prefer sameness. They often have obsessive routines and are often preoccupied with a particular subject of interest. They are often unable to accurately read nonverbal cues (body language) and often are poor judges of determining proper body space. Individuals with AS generally have an average or above average IQ. Many have exceptional skills or talents. Many individuals with AS are viewed as eccentric or odd. They easily become victims of teasing and bullying. While they appear to have normal language and their language skills seem to be well developed, individuals with AS often have deficits in pragmatics and prosody. Individuals with AS are extremely literal, often do not understand the use of sarcasm, and have difficulty using language in a social context (Kirby, 2007). Aggressive behaviors are common and over represented in those with AS (Gillberg & Billstedt, 2000).

Consider the following scenario: Two little girls were playing in a park and the first little girl says to her friend, "When I grow up, I want to be a mom." The second little girl responds, "When I grow up, I want to marry a prince!" Both little girls giggle and smile. They continue their conversation talking about the boys they will marry, the houses in which they will live, and the perfect children that they will raise.

Wouldn't it be nice if our dreams of children and family always came true? The reality is that dreams often do not come true, at least not in the way we envision them. My dream of having the perfect family dissolved the day I realized that my son, my beautiful baby boy, was not developing like his neurotypical peers.

For years I was told that I was doing everything correctly, my parenting strategies were intact, and with a little more effort, the joys of raising a son would flourish. But, week after week and year after year, the frustration of parenting my little boy was taking its toll not only on me, but on my husband, our other children, and our marriage. It was not until my son was visiting his psychiatrist for the colloquial medication evaluation when the word Autism was first suggested.

Autism was the suggested diagnosis! This came as an unexpected and unanticipated shock. Since my son was 7, he had been diagnosed with Oppositional Defiant Disorder. Behavior modification, insight-based behavior plans, a parade of therapists, and the most well intentioned professionals told us time and again that they did not know what else we could do to help him. In addition to life-threatening food allergies, we had been dealing with school challenges, lack of peer relationships, intolerant neighbors and family members, and feelings of hopelessness and helplessness. Our marriage was strained, arguments were common, and our other two children were often ignored or missed out on healthy family interactions due to our struggles with our son.

The tension in my house was constant. Why was life so hard for our family? What were we doing wrong? Why couldn't anybody tell us what to do differently? What could we do to help our son, maintain our family system, and keep our sanity? Subsequent testing and interventions led us to a definitive diagnosis of Asperger's Syndrome for our now 12-year-old, deeply troubled, hopelessly lonely, and desperately isolated child and family. Now, we had the right diagnosis with which to work, live, heal, and proceed. What next? We had few, if any, family friends, we lived 200 miles from our closest family members, and we had missed out on 12 years of intervention for our son and our family.

Our family strengths helped us continue in spite of the ongoing struggles. We were still married, our other children seemed to be flourishing, and the police were not yet on a first name basis with us! But, where was the support and information from which we could have benefited for the past many years? Were there other strategies out there that could have helped support my family in a more productive and successful manner?

FOCUS OF THIS RESEARCH

The focus of this research was to investigate how other families living with Asperger's Syndrome have been affected by this disability. Having a child with a disability shatters the idealistic dreams of life's expected course held by most families. Some of the questions with which families are faced and that I explored in this study include:

1. Now what does the future hold for the child, the family, and others impacted by the disability?
2. Will marriages or significant relationships survive?
3. Will neurotypically developing children be negatively affected?
4. Where will families find the support and guidance from their communities and professional helpers that they need?
5. What will life look like for these families in 5, 10, and 20 years?
6. How do these families find their place in the world, the support systems that they need, and the resources necessary to keep their family as healthy and well functioning as possible?

These are the questions I want to explore in this research study. Not only is this a subject close to my own heart, but it is one that impacts families all over the world at ever increasing rates.

RESEARCH QUESTION

The operating research question of this project thus is: What is it like living in a family with a family member diagnosed with Asperger's Syndrome? The goal of this study is to increase our understanding of the ways that Asperger's Syndrome affects families so that improved therapeutic interventions can be developed to support these families. It is hoped that this research will contribute to the growing literature on autism spectrum disorders in a positive way. It is further hoped that this information will lend itself to the continued development of improved interventions and supports for these families by increasing the knowledge base of what it is like living with the disability.

It is my hope that this study will be used to enlighten professionals working with families living with Asperger's Syndrome to better understand the struggles families face. In that end, service to these families should improve as understanding is heightened. With the number of families living with Asperger's Syndrome growing, it is our duty as social service practitioners to research this growing disorder, develop strategies, create tools, and identify creative intervention techniques to meet the ever growing and unique needs of the families affected by this complex disability.

It can be argued that this assumption is limiting. It is true that a myriad of variables impact the functioning level of family. It is also true that autism and Asperger's Syndrome is only one of the many issues that can impact a family. However, increasing the understanding of this specific variable, living with Asperger's Syndrome and its impact on the family system, can only lead to an increase in positive outcomes for families impacted by this disability. Based upon this assumption, the following review of literature will provide an overview of autism and its related impact on the individual. Limited data exists on the outcomes for families, another reason why this study should be a valuable addition to the ever growing research on autism and autism spectrum disorders.

HISTORY OF AUTISM

Autism was first identified in the early 1940s (Fombonne, 2003). Since the disorder was named, it has been a puzzling, complicated, fascinating, and vastly researched disorder. It was first believed that autism was an early form of childhood schizophrenia. The word "autism" was first used by Bleuler to identify a cardinal sign of schizophrenia. This interpretation of autism led to thirty years of controversy about the validity of autism as its own distinct syndrome. Other terminology used for autism included "infantile schizophrenia," "early childhood psychosis," and "symbiotic psychosis." These terms prevailed until the late 1960s (Fombonne, 2003).

The first account of autism without an association with brain damage, mental retardation, developmental language disorder, or a history of childhood abuse or neglect dates back to 1747 legal case. Hugh Blair, age 39 and the son of a Scottish landowner, had his mental capacity challenged in court by his brother over family money. Hugh's personality was described as tactless. His gaze was described as abnormal and he was said to have a severe retardation and abnormality in his speech which included echolalia. He was further described as displaying obsessive and repetitive behaviors, having odd motor mannerisms and collections, and was noted to always sit in the same seat in church. He insisted that domestic objects retain their same place in the home and exhibited a lack of common sense. He was even said to have a "silent madness" (Wolff, 2004).

Other early contributors to the identification of autism include Dr. John Halsam's 1809 publication "Observations on Madness and Melancholy" and Dr. Henry Maudsley's

1879 publication "The Pathology of Mind." These works were greatly respected by Leo Kanner, a child psychiatrist from Baltimore, Maryland (VanBergeijk, 2005). Kanner identified autism as "autistic disturbances of affective contact" (VanBergeijk, 2005, p. 25) and successfully convinced the psychiatric world of autism's existence in 1943 (Wolff, 2004).

Original misconceptions about the etiology of autism included the most negative: that autism was caused by poor parenting (Wolff, 2004). Kanner pointed to disturbances of affective contact occurring in infancy and to unusual personality traits in parents as key contributors to the disorder. The misconception of autism being an infant's response to early disturbance of the mother-child relationship (called the "refrigerator mother") has fortunately long since been discarded (Fombonne, 2003).

A second misconception about autism is that the disorder fell within the realm of schizophrenia. Autism has been definitively identified as a developmental disorder, not a psychosis. This is significant in so much as the classification of a disability plays a large role in the support and intervention services that the individual and his/her family are able to access.

A third misconception about autism is that it is secondary to a developmental receptive language disorder and not its own distinct disorder. A fourth misconception is that siblings of autistic children have no increased risk of having the disorder (Wolff, 2004).

Research has shown a strong genetic link to autism with multi-generational family members exhibiting classic autism or autistic tendencies. The understanding of autism continues to evolve. It is significant to note that research has taught us that autism involves communication impairments, not language impairments (Fombonne, 2003).

PREVALENCE

The prevalence of autism has increased over the years from 4-5 per 10,000 to around 6 per 1,000 children (Wolff, 2004). The number of children affected by Asperger's Syndrome doubles the number of children who exhibit classic autism (VanBergeijk, 2005).

The prevalence of Asperger's Syndrome is considered to be much higher than autism. Its prevalence is believed to be about 26-28 out of 10,000 school-aged children (Schnur, 2005). Total number of affected individuals is similar between racial groups but varies among male to females, with an average ratio of 4:1. The highest male to female ratio is seen in African American people (Schnur, 2005).

DEFINITIONS

Definitions are included to help the reader understand the following research.

Neurotypical in the context of this study refers to the development of a child within the normal and expected parameters of child development as judged by the general population. Neurotypical is a newly developed term used for individuals with a normally developed brain; a person who is non-disabled or non-autistic (http://www.iancommunity.org/cs/glossary_term?glossary.id=66, accessed 11/24/2008).

The term was developed and is used among the autistic community as a label for non-autistic persons.

Autism is a developmental disability that is present from birth or very early in development. It affects social interaction, the ability to communicate ideas and feelings, imagination, self-regulation, and the ability to establish relationships. Autism is estimated to occur in as many as 1 in 166 individuals (Center for Disease Control and Prevention, 2008) and is being diagnosed at alarmingly increasing rates in children today. Autism is four times more prevalent in boys than in girls and knows no racial, ethnic, or social boundaries. Family income, life-style, and educational levels do not affect the chance of a child having autism.

The prevalence of Asperger's Syndrome is considered to be much higher than autism. Its prevalence is believed to be about 26-28 out of 10,000 school-aged children (Schnur, 2005). Autism is thought of as a spectrum disorder. The severity of symptoms differs in people. Three diagnoses on this spectrum disorder include Autism, Asperger's Syndrome, and Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) (http://www.ausm.org/autismInfo/index.asp, accessed 11/24/2008).

Chapter II

REVIEW OF LITERATURE

INTRODUCTION

Ponder for a moment the image that comes to mind when thinking of the term family. For most of us, we imagine a combination of adults and their children. Some families are large and some are small, but for most, these images include visions of joyful events, birthday parties, graduations, college send offs, weddings, job promotions, and grandchildren. Now consider a family that includes a child with a disability. How does that image change?

The purpose of this research project was to increase our understanding of the impact that a disabled child has on his/her family system. In this study, the focus will be on Autism Spectrum Disorders (ASD) and specifically the disorder of Asperger's Syndrome (AS). My hope is that the information learned from this project will increase understanding of the experience of the AS family. My hope also is to enlighten those working and supporting these families in order to help enhance the quality of life enjoyed for all members of the family living with Asperger's Syndrome.

To understand ASD/AS and how this disability impacts the family system, it is important to understand the disability and the life circumstances of those who live with it. Because AS is a spectrum disorder affecting each AS individual in a unique way, there are many topic areas included in this review of literature. It is important to have a broad understanding of the vast number of dynamics and internal and external systems that impact and are impactful to the life of the AS individual and the family who cares for him/her.

This review of literature is organized into three main sections: Diagnostic Issues, Treatment and Interventions, and Family and Community Issues. The section on diagnostic issues focuses on research into the causes and treatment of Autism, the DSM-IV-TR, comorbidity issues, an explanation of pervasive developmental disorders, and a segment on special interest areas (SIA). The middle section of this chapter focuses on treatment and interventions which include medical interventions, theories on how the brain processes information, and several examples of therapeutic treatments and interventions used with the AS population. The final section of this chapter focuses on the impact of AS on the family and community. The topics in this section include the impact AS has on parenting, siblings, the marriage and family. The literature on the affect of AS on friendships, victimization the AS individual experiences, educational implications, general and adult outcomes will also be explored.

DIAGNOSTIC ISSUES

Research Into the Causes and Treatment of Autism

Research into the causes and treatment of autism and autism spectrum disorders is a growing field and has received increasing financial support. In 1997, the United States National Institute of Child Health and Human Development committed to a 5-year program with a budget of $42 million. An additional $65 million was committed to research in 2002. The Centers for Disease Control has funded seven states to conduct intensive epidemiological surveys of autism while another five states have been given funding to conduct additional research into autism. Internationally, the United Kingdom and Canada have committed major funding to the research and understanding of autism (Fombonne, 2003).

DSM-IV

Asperger's Syndrome was added to the *Diagnostic and Statistical Manual of Mental Disorders*, 4th Edition (DSM-IV; American Psychiatric Association, 2000). The DSM-IV approach has been to adopt a triad of symptom clusters used in the definition of autism. These include qualitative impairments in social interaction and communication and restricted repetitive and stereotyped patterns of behavior. DSM-IV makes the distinction between autism and AS solely on the basis of the onset criteria (Klin et al., 2005). AS is also defined in *the International Statistical Classification of Diseases*, 10th Edition (ICD-10) and was added in 1990 (VenBergeijk, 2005). Asperger's Syndrome is clinically differentiated from autism and high-functioning autism by the absence of clinically delayed speech (Schnur, 2005).

Diagnostic Criteria include:

A. Qualitative impairment in social interaction as manifested by at least two of the following:
    - Marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.
    - Failure to develop peer relationships appropriate to developmental level.
    - A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people).
    - Lack of social or emotional reciprocity.

B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
    - Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
    - Apparently inflexible adherence to specific, nonfunctional routines or rituals.
    - Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements).

- Persistent preoccupations with parts of objects (Kirby, 2007).

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific Pervasive Developmental disorder or Schizophrenia (Kirby, 2007).

It can be complicated to definitively make the diagnosis of Asperger's Syndrome. Some of the characteristics are social, some are developmental, and some are attentional. Since the development of atypical traits may be obvious, the warning signs may be identified easily and an assessment might be sought out. Other characteristics of the syndrome are more discreet and less easily identified. Because language development usually is not delayed, genetic factors are not outwardly visible, and the issues may be misdiagnosed or the diagnosis may be delayed, the typical age of diagnosis for AS is 11 years. Parents can generally trace concerns regarding their child's development to as early as 30 months of age. It is critical that the clinical assessment of a child for AS is completed by an interdisciplinary team and should include a developmental health history, an assessment of communication and psychology, and a diagnostic exam (Schnur, 2005).

Comorbidity

Autism has a strong association with seizures and mental retardation (Fombonne, 2003), speech and language disorders, and hearing and visual impairments (Gillberg & Billstedt, 2000). The onset of epilepsy in autism often occurs in adolescence or early adulthood and its incidence is between 18-20% (Howlan, 2000). It is highly likely that a person with the diagnosis of AS will also have a secondary mental health diagnosis. Co-morbidity is often the rule with this population (Ghaziuddin, 2002). Common secondary diagnoses include motor disorders, clumsiness, sleep problems, abnormal sensory responses, attention deficits, and abnormal activity levels (Gillberg & Billstedt, 2000). The rate of those with AS being underweight and/or having eating disorders is increased. Texture of food seems to play a big role in the sensory piece of eating for the individual with AS (Gillberg & Billstedt, 2000).

Environmental stressors for individuals with AS are likely to increase their vulnerability to mood and anxiety disorders due to their typical social isolation and high levels of frustration with social interactions. A high incidence of depression and bipolar disorder exists with AS individuals (VanBergeijk, 2005).

The age of the AS individual influences the type of secondary diagnosis they possess. In past studies, 25% of children with AS had depression, while 53% of adults and teens with AS were diagnosed with depression (VanBergeijk, 2005).

Children are likely to hold a secondary diagnosis of Attention Deficit Hyperactivity Disorder (ADHD). In some cases, ADHD is diagnosed prior to the diagnosis of AS. The unpredictability of the social environment and the individual with AS's difficulty in navigating the social world often leads to a diagnosis of anxiety and anxiety related disorders including social phobias. Some with AS develop compulsive rituals which help them manage their stress. This leads many psychiatrists to think that the AS individual is displaying obsessive-compulsive disorder (OCD). The prevalence of Tourette's Syndrome (TS) in the AS population is four times higher than that in the general population. (VanBergeijk, 2005).

Pervasive Developmental Disorders

Autism and Asperger's Syndrome. Autism and Asperger's Syndrome are considered Pervasive Developmental Disorders (PDD). PDD is an umbrella term which refers to a spectrum of disorders. These disorders differ with respect to the number or type of symptoms present, or the age of onset of the symptoms. Others consider Asperger's Syndrome (AS) in terms of an Autism Spectrum Disorder (Schnur, 2005). Others conceptualize AS as an extreme form of high-functioning autism (Ghaziuddin, 2002) and others call it the "Geek Syndrome" (Kaufman, 2002).

Autism spectrum disorders are conceptualized as a continuum of syndromes ranging from Autistic Disorder to Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). This continuum includes Rett's Disorder, Childhood Disintegrative Disorder, Atypical Autism, and Asperger's Disorder. All are listed in the

DSM-IV-TR, 2000 (VanBergeijk, 2005). Noted researcher, Lorna Wing, is credited with changing the epidemiology of autistic conditions to the concept of the autism spectrum (Wolff, 2004).

The concept of a spectrum disorder is helpful insofar as the ideas of severity of symptoms are more easily understood. An individual diagnosed with Autism would be identified on the lower functioning end of the spectrum while an individual diagnosed with AS would be identified on the high end of the spectrum. In terms of the spectrum, AS lies between Autistic Disorder and PDD-NOS (VanBergeijk, 2005).

'The Child with low-functioning autism lives in a world of their own, but the child with Asperger Syndrome lives in our world but in their own way' (Van Krevelen, cited in Williams, 1995, p. 9, cited in Sefran, 2001, p. 151). This understanding of the world for an AS individual is unique from both the autistic individual and the neurotypical individual. It is critically important to remember that the AS individual perceives the world in their own unique way. Many of the behaviors that seem odd or unusual are due to their neurological differences and not the result of intentional rudeness, bad behavior, or the result of improper parenting (Kirby, 2007).

Special Interest Areas

One of the unique features of Asperger's Syndrome is the special interest areas (SIA). A SIA is a topic, item, or theme in which the AS individual maintains a special interest which can often monopolize their thoughts, actions, and behaviors. SIA are often intellectual in nature such as an interest in math or science or specific in nature such as a preoccupation with trains or dinosaurs. In addition to this characteristic and the impact it has on the affected individual, the SIA significantly affect the entire family system. SIA seem to be a dominant characteristic occurring in over 90% of children and adults with AS. Deficits related to their disability seem to diminish when individuals with AS are actively engaged in their SIA (Winter-Messiers, 2007). The response of those not impacted by AS in the neurotypical world to the SIA of the AS individual depends largely on the nature and topic of the SIA. Little research has been conducted on this topic (Winter-Messiers, 2007).

Parents and educators frequently see the SIA as annoying, socially inhibiting, and sometimes harmful. The SIA is often viewed as a behavior to extinguish. Another view of SIA is that the SIA captures the passion, mind, heart, time, and attention of the individual with AS, and provides them a lens with which to view the world. Common themes of SIA include transportation, music, animals, sports, video games, motion pictures, woodworking, and art. A common SIA among young autistic children is Thomas the Tank Engine. In 2002, a study found that 57% of children on the spectrum associated with Thomas before any other children's character, and retained their interest for two years beyond their neurotypical counterparts (Winter-Messiers, 2007).

It is speculated that SIA may be the AS individual's attempt to find ways of understanding society. SIA tend to be inextricably entwined with the AS individual's self-image. When individuals with AS are engaged in their SIA, they generally feel positively about themselves. This is in contrast to their usual feelings of being misunderstood and frustrated. AS individuals will actively engage in their SIA to self-regulate stress and anxiety and to calm themselves. It is unclear as to what the origins or development of SIA and why they develop. SIA hold much promise for individuals with AS. As Hans Asperger stated (1944):

> Able autistic individuals can rise to eminent positions and perform with such outstanding success that one may even conclude that only such people are capable of certain achievements. It is as if they had compensatory abilities to counter-balance their deficiencies. Their unswerving determination and penetrating intellectual powers, part of their spontaneous and original mental activity, their narrowness and single-mindedness, as manifested in their special interest, can be immensely valuable and can lead to outstanding achievements in their chosen areas. (Winter-Messiers, 2007, p. 150)

INTERVENTIONS AND TREATMENT

Medical Interventions

Medical intervention can play an important part into the success and impact of the disability on the individual and family. Little evidence-based information exists about pharmacological treatments of individuals with AS (Tsai, 2007). Individuals with AS are often treated with psychotherapeutic medications for maladaptive behaviors and the symptoms associated with their co-morbid conditions. Medications do not cure AS. However, they can lessen the challenges to the AS individual and their family members, and improve their quality of life (Tsai, 2007).

The validity of self-reporting medication needs, side effects, and value of medication by individuals with AS has not been established. It is crucial that a complete functional behavioral analysis be completed by a qualified and experienced professional before an individual with AS is referred to a primary physician or psychiatrist for medication treatment (Tsai, 2007). Because it is common for individuals with AS to have communication deficits, they may not be able to comprehend or recognize the side effects and may be unable to manage the side effects or inform their caregiver of the difficulties they are having. This often leads to increased frustration and medication noncompliance (Tsai, 2007) thus adding increased challenges to the family and caregivers. Some of the medications used by AS individuals that have had positive results include stimulants, antidepressants, medications for anxiety disorders, medications for OCD, medications for Tourette Syndrome, and sleep aids (Tsai, 2007).

Theories of How the Brain Processes Information

Theory of mind. Cognitive psychologists developed the term 'Theory of Mind' to explain how individuals understand the internal mental states of others (metarepresentation), including intentions, beliefs, needs, and desires. Theory of mind recognizes that another person's belief is based on his experience or knowledge and not necessarily on what we know to be true (Jacobsen, 2004). A neurotypical child will develop theory of mind around age 4. Not all children with AS are able to develop this skill. If able to develop this skill, the development is usually delayed and more common between the ages of 9-14. If developed, these skills are only developed after very slow, effortful learning (Safran, 2001). Most individuals with AS can understand another person's mind, only to the extent that they know what knowledge another person has (Jacobsen, 2004).

Central coherence. Central coherence is also described as global vs. local processing and is the process of constructing a higher meaning from diverse information. When an individual has weak central coherence, the individual focuses on details without relevance to a central meaning. Neurotypical individuals are able to recognize the global gist of information without necessarily remembering the details. Individuals with AS have difficulty separating the gist of the story from the details even when they understand the global story (Jacobsen, 2004).

Executive functioning. Executive Functioning is the capacity to control one's own attention and focus. It enables the individual to do or to attend to more than one thing at a time, recognize what is most relevant, and easily shift attention. It is very important for neurotypical individuals to understand executive functioning and how poor executive functioning impacts AS individuals. Children and adults with AS will not just naturally notice what is obvious to the neurotypical individual. Information must be presented to the AS individual in a straight forward manner, without irritation, and in the most natural and concrete way possible. Language used must be clear and concise. Direction and correction must be given in a positive way. Therapeutic intervention must address awareness of this deficit in the AS individual (Jacobsen, 2004).

Therapeutic Interventions and Techniques

Individual therapy as maintenance of the family unity is important in working with each AS child (Lozzi-Toscano, 2004). Evidence has shown that intensive and early individualized education alters outcomes for all children with AS (Schnur, 2005). No two individuals with AS are alike thus indicating that creative measures must be used to tailor treatment plans to each affected individual's specific strengths and deficits (VanBergeijk, 2005).

AS individuals and family systems can pose enormous challenges for counselors. Psychoanalytic theories do not generally help with understanding the AS individuals. Psychoanalytic theories and therapy assumes that there are reasons for and meaning behind thoughts and behaviors. This expectation is not useful with a child who has AS (Jacobsen, 2004).

Most counselors are comfortable handling children with behavioral issues because behavior can be modified with medication and various treatment strategies. Families and children dealing with AS have many more complex issues dealing with social interaction, communication, classroom challenges, and family dynamics. It is important to educate those around the AS child and adapt the world to the child rather than expect the child to adapt to a world he/she cannot understand. It is very important to aid the child in establishing behavioral cues that will enable him/her to self-regulate (Lozzi-Toscano, 2004).

Individual counseling can be helpful with AS individuals and families. A one-to-one relationship with an AS individual can give them structure, guidance, information, and support that they can use to function more effectively in society. Understanding the AS individual's worldview, developing rapport and trust, assisting them with analyzing their thoughts, feelings, and perceptions, facilitating their understanding of the impact of their behavior on others, and helping them to deal with day-to-day situations can lead to successful therapeutic involvement. The transition from adolescence to adulthood can be delayed and prolonged (Stoddart, 1999).

Working with an AS individual requires the counselor or therapist to understand that there will be no "aha" moment with regard to the emotional experiences of the individual. The "aha" moment comes from intellectual understanding for the AS individual. Intellectual knowledge forms the bases of understanding on how to deal with the world (Jacobsen, 2004).

Treatment and interventions should focus on negotiating the social environment and learning situation-specific social skills. Insight oriented therapies are not recommended for the AS population. On the other hand, cognitive and behavioral therapies have offered many positive outcomes for AS individuals. These types of therapies directly teach social skills and strategies for interpreting and managing social situations. (Lopata et al., 2006). The Cognitive Behavioral Therapy model (CBT) presumes that social perception processes can be taught cognitively and can influence behavior (Bauminger, 2007).

Another type of therapy showing good potential for the AS individual is Cognitive Orientation for Daily Occupational Performance (CO-OP). CO-OP is a client-centered, cognitive approach to acquisition of occupational skills. AS children are taught a global problem solving framework and are guided to discover Domain Specific Strategies to enable mastery of their chosen skills. A major focus of CO-OP is on the generalization and transfer of learned strategies and skills to everyday life (Rodger, Springfield, & Polatajko, 2007).

No single profession currently possesses the knowledge and skills to effectively assess and treat a syndrome as complex as Asperger's (VanBergeijk, 2005). Boundary setting, clear structure, and routine are some of the other key therapeutic interventions found to be successful with AS children (Lozzi-Toscano, 2004).

Applied Behavioral Analysis (ABA) principles have shown that substantial cognitive and language gains can be achieved and maintained when used intensively with autistic children (Fombonne, 2003). ABA dissects behaviors into their smallest components-stimuli and response; this may not be adequate for real children in real classroom settings as behavior occurs in streams, not in isolation, and it is often difficult to identify a clear antecedent to or a clear consequence of behavior (Strain & Schwartz, 2001). Training in behavior management and vocational counseling are also important interventions for the success of the AS individual (Schnur, 2005).

AS is seen through a number of different lenses by professionals. Occupational therapists often see AS as Sensory Integration Dysfunction; Psychiatrists sometimes use the term Schizoid Personality Disorder; Neuro-psychologists use the term, Non-Verbal Learning Disability (NLD), and Speech Pathologists conceptualize AS with the term Semantic Pragmatic Disorder (SPD) (VanBergeijk, 2005).

Many individuals with AS can also benefit from occupational therapy. This therapy can enhance find motor developments and vocational skill development (Griffin et al., 2006).

FAMILY AND COMMUNITY

Parenting

Studies have found that there is an excess of mood and anxiety disorders in the parents of individuals with autism (Ghaziuddin, 2005). Parents of children with AS are challenged greatly by the uneven development of their children and are at increased risk of developing psychological difficulties (Pakenham, Sofronoff, & Samios, 2004). Controlled studies of parenting styles and family behaviors indicate that parents of children with autism are no different in their parenting styles then parents of neurotypically developing children (Fombonne, 2003). With regard to special interest areas, parents express a wide range of emotions concerning their AS child's special interests. Positive emotions include pride, humor, fascination, pleasure, and enthusiasm in their child's special skill or knowledge. Negative emotions include boredom, frustration, and embarrassment (Winter-Messiers, 2007).

Parents of AS children report higher family strain then parents of neurotypically developing children. Mothers report greater stress and poorer adjustment compared to mothers of children with Down Syndrome and mothers of children with mental retardation (Pakenham, Sofronoff, & Samios, 2004). Stress levels seem to be higher for mothers than for fathers. The stress of raising an AS child has very different meanings for mothers and fathers. Stressful life events cause more psychological distress and depression in women, especially when the events affect people with whom they have an emotional relationship, such as family and friends (Gray, 2003). For men, fathers seem to become more emotionally distressed by stressful events related to work or family finances. Coping mechanisms differ from men and women as well. Men are more likely to engage in problem focused coping while women tend to engage in emotion focused coping. Mothers tend to blame themselves for the child's problems. They tend to feel as if their own identities are threatened by disability in their children. Women's careers are greatly affected when trying to raise a disabled child. Most often, men's careers are not affected by having a disabled child. Fathers do express considerable concern about the futures of their disabled children (Gray, 2003).

Mother's stress level can best be predicted from the number of problematic behaviors of the child, not by the child's adaptive behavior or autistic symptoms. Children's troubles with schoolmates are also associated with the mother's emotional stress level. It seems that the mother not only is the primary person who generally deals with school issues, but also with medical appointments, community challenges, and sibling discord (Gray, 2003).

Hardiness and coping styles serve as predictors of good adaptation of the mother to the child with AS. The relationship of a mother to the father is also a source of stress for the mother. The father's support in terms of verbal expression has been shown to serve as a predictor of the course of care to the affected child. A father's cooperation and support are necessary to alleviate the stress on the mother. It is postulated that, for the sake of mothers, the father should try to avoid dominative and intrusive attitudes and behaviors, and support the mother emotionally, as well as physically (Yamada et al., 2007).

The family's ability to adapt to the challenges of raising an AS child are shaped by other factors including severity of the stressor (child's disability), ever increasing demands/additional life stressors, family resources (social supports), cognitive processes involved in changes the family makes to their definition of the situation, and coping strategies. Studies have shown that the most positive outcomes are related to parents who have been able to make sense of the diagnosis and find the positives in coping with and raising a child with AS (Pakenham, Sofronoff, & Samios, 2004).

Siblings

Because children with AS show serious interactive impairments, the siblings of these children are frequently exposed to multiple behavioral and social maladjustment problems in their family environment (Dellve et al., 1999) with aggression by the AS sibling as being the most common stressor (Ross & Cuskelly, 2006). Anger was found to be the strongest emotion displayed by siblings (Ross & Cuskelly, 2006). Coping skills become an extraordinarily important skill for these siblings to possess. Since many siblings of children with AS are aware of the level of anger that aggressive behaviors produce in them, many choose to cope by actively controlling their emotions and internalizing their emotions and own difficulties. This can lead to poor outcomes (Ross & Cuskelly, 2006). Coping abilities among children and adolescents are different from the coping abilities used by adults. These coping skills differ in terms of how the child and adolescent deal with gaining independence, gaining understanding, and balancing life responsibilities (Dellve et al., 1999).

Brothers and sisters of AS children need an honest and truthful explanation of their sibling's disorder (Schnur, 2005). A positive correlation was found between the quality of the relationship and the sibling's knowledge about the disability (Dellve et al., 1999; Ross & Cuskelly, 2006). This is important because the sibling may not receive as much parental attention due to their special needs sibling's demands on parental time (Schnur, 2005). Siblings may need support as well as there is a unique stigma attached to having a sibling who looks "normal" but has odd behaviors (VanBergeijk, 2005).

Reviewed studies in a Dellve et al. study (1999) showed that 60% of siblings were at increased risk for maladaptive behaviors due to living with an AS sibling. There was a greater risk for developing psychosocial problems, fear of being defective like the AS child, and feelings of anger, and guilt toward the increased parental demands of the affected child. Several positive effects among healthy siblings were also identified. These include maturity, sensitivity and enhanced compassion, high levels of involvement in the affected sibling's life, strong feelings of responsibility, and an emphasis on the positive aspects of the family's life (Dellve et al., 1999).

A study by Toth et al. in 2007 showed that siblings as a group were below average in expressive language and composite IQ and had lower scores on their receptive language, adaptive behavior, and social communications skills, used fewer words, gestures, and social smiles as compared to like age counterparts. The development of young non-autistic siblings is affected at an early age by their autistic sibling and must be closely monitored and offered appropriate interventions as deemed appropriate (Toth et al., 2007).

The sibling interactions are an important factor in understanding and impacting the social functioning of the AS child (VanBergeijk, 2005). Parenting style, parent distress, and family coping style and adaptation may be the most important facet in influencing the adjustment of siblings of children with AS (Ross and Cuskelly, 2006).

Marriage/Parents/Family

Autism ranks among one of the most challenging of all developmental disabilities that can exist in a family, when considering the stress a developmental disability causes to a family. Problems with communication, emotional expression and antisocial behaviors, all combined place tremendous stress on the family (Gray, 2006). According to the US Census Bureau, approximately 16% of marriages end in divorce prior to the couple's fifth anniversary, 35% prior to the 10th anniversary, and 48% prior to the 15th anniversary (http://www.divorcemag.com/statistics/statsUS.shtml,2008). The kind of chronic stress that raising a child with special needs entails, stresses relationships to their weakest points; as many as 80% of these marriages end in divorce (http://asa.confex.com/asa/2006/techprogram/S1940.HTM, 2008). The whole family needs support, counseling, in-home help, and respite care to manage their special needs child (Schnur, 2005).

Social patterns at home can and should be incorporated into the evaluation process as strengths for the AS individual (VanBergeijk, 2005). Coping strategies change over time for families and individuals. Research indicates that there is a tendency for young adults to use problem-focused coping strategies to deal with stressors. These young adults tend to change the nature of the problem in order to cope with the problem. An example would include a person frustrated with his job coming home and verbally attacking his family instead of expressing his frustration by talking about his frustrating work issue. Middle-aged adults use emotion-focused strategies; this coping strategy distracts the attention of the individual affected by a stressful situation with other emotion-based issues (Gray, 2006). The perceived success and outcome of family life is impacted by the expectations of what those family members consider to be success, and the capacity in which the family is able to cope and meet the needs of their AS child. In general, mothers are more likely to perceive their family more abnormal than fathers (Gray, 1997).

Friendships

Social dysfunction might be the single most handicapping feature of AS (Carrington, Templeton, & Papinczak, 2003). Peer support and peer learning should be recognized as significant goals for intervention. Many individuals with AS can trace their adult ongoing difficulties to a lack of understanding and support in their childhood (MacLeod & Johnston, 2007).

Although friendships are desired, the individual with AS lacks an understanding of reciprocity and sharing of interests which are key features of friendship. Individuals with AS have deficits in communication and have difficulty in developing appropriate relationships with peers despite their intellectual capabilities. One reason for these difficulties is that AS individuals have difficulties with information presented to them in the oral fashion. Rigidity in thinking also causes challenges in establishing peer relationships as does their propensity for intense focus on their special interest areas. Individuals with AS are unable to appreciate that in some situations, rules can be bent or broken. Friendships that do develop tend to revolve around very specific interests such as computers and video games. High school students are become increasingly aware of their differences, developing a coping strategy of masquerading in an effort to mask their differences. The high school years generally represent a huge challenge for AS children because high school is a time of coping in a larger environment, dealing with a more diverse population, and expectations of conformity and social competence is emphasized (Carrington, Templeton, & Papinczak, 2003).

Victimization of the AS Individual

Due to their unusual mannerisms, view of the world, and social deficits, individuals with AS are often targets of victimization and bullying. Children with AS are often described as "perfect victims" by their peers because of their profound lack of social skills. Prevalence rates of victimization reported by mothers of AS children was 94% in a study conducted by Little in 2001. Mothers reported that almost three quarters of their AS children had been hit by peers or siblings in the past year and 75% had been emotionally bullied. Ten percent of the children had been attacked by a gang and 15% had been victims of nonsexual assaults to their genitals. Peer shunning was also a commonly reported incident. A third of the AS children had not been invited to a single birthday party, and many ate alone and were picked last for teams during school gym classes (Little, 2002).

Short-and long-term negative health outcomes have been attributed to ongoing peer victimization. Greater incidences of depression, low self-esteem, anxiety, loneliness, and lower academic achievement of these victimized youth have been reported. In fact, AS children victimized during middle school was a valid predictor of depression and low self-esteem 10 years later into their adulthood (Little, 2002). Younger male children with AS are more likely to be hit by peers and siblings while older children with AS are more likely to be shunned by their peers (Little, 2002).

Education

A significant portion of time in a child's life is spent in school. The impact that the educational setting has on the AS individual has a profound impact on how the AS individual functions outside of the educational environment and within his/her family setting. Appropriately designed educational programming will meet the AS individual's educational needs within an environment that fosters social inclusion and minimizes the frustrations that AS individuals encounter due to their social processing deficits. An ineffective educational program will leave the AS individual frustrated and unregulated. The AS individual will return to his/her family, generally a safe place, and decompress by taking out his or her frustrations on the family members while attempting to manage and/or cope with his/her emotional distress and social confusion of the day.

Children with autism benefit most when: home and classroom environments are structured to capitalize on their individual strengths and compensate for their deficits; the classroom offers a high teacher to pupil ratio with individual educational plans (IEP); and parents acted as co therapists to promote the child's generalization of learning (Fombonne, 2003). In-class and after-school activities are shown to be significantly important facets to the assessment and programming plans for the AS student (VanBergeijk, 2005).

Students with AS historically have not received equitable educational accommodations in terms of support, services, and resources as compared to students with classic autism. AS students have been called orphans in the educational system (Barnhill, 2007). Emerging educational practices include social skills training, social stories, and structured teaching (Safran, 2001).

Interventions for individuals with AS are most effective if they are consistently implemented, use concrete information and visual structures, and utilize the assistance of parents, teachers, peers, and therapists. The most effective school-based programming will include a highly consistent and well structured school day, systematic social skill and language training, social mentoring, and modified instruction and assignments including pre-teaching (Griffin et al., 2006). AS children must be protected from bullying and teasing and have limited time to engage in isolated activities (Griffin et al., 2006).

Special programming approaches have been developed to encourage positive peer-related social experiences while learning useful skills in a supportive atmosphere (MacLeod & Johnston, 2007, p. 83). Two models include The Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) program and the Social-Behavioral Learning Strategy Intervention (SODA). Both have shown positive results.

Higher education for the AS individual is possible with the appropriate modifications. Best practices in working with this population continue to be developed (Smith, 2007). Visual supports have shown benefits. Assistive technology such, as the use of a PDA, has the potential to help students with AS overcome daily difficulties, lower their frustration levels, and allow for greater independence (Smith, Ferguson, & Hagiwara, 2007).

General Outcomes

It can be argued that life's course is shaped by levels of influence imposed through the interplay among the individual, family, school, peers, and community factors. One of the most significant impacts on a child's life course is his own participation through the course of everyday activities and through ongoing interactions with others. This relationship between learning and development is called proximal processes (http://www.comnet.ca/~pballan/Vygotsky(1978).htm, accessed 12/08/08). The development of the individual is considered to be mutually influenced by the roles of the child and his environment.

Autism is a lifelong handicap (Fombonne, 2003). The extent of the social challenges for the AS individual include their profound sense of isolation, difficulty in initiating social interactions, challenges relating to communication, longing for great intimacy, desire to contribute to their community, and effort needed to develop great social and self awareness (Muller, Schuler, & Yates, 2008). The primary objective for the family of an individual with AS is to create a supportive family environment and a responsive educational environment (Gable, 2005). The behavioral adjustment of children with autism can be much improved with early intervention but there is no long term outcome prognoses as of yet (Wolff, 2004). The effects of AS are greatest in adolescence and young adulthood (Jennes-Coussens, Magill-Evans, & Koning, 2006) and can add additional strain on the care giving primary family. The risk of overall deterioration of functioning in adolescence or early adulthood seems to be the highest in individuals with lower IQs. In the higher functioning group, adolescence sometimes brings about improvement in functioning (Howlin, 2000). Many young men with AS report feeling happier and less stressed once they finish or quit high school. One-third of individuals with AS were neither working nor going to school. Studies have shown that men ages 18-21 report a significantly lower social and physical quality of life then of their neurotypical counterparts.

Quality of life is defined as a person's position in relationship to his context and goals and is affected by physical health, psychological state, level of independence, social relationships, and relationships to the environment. An AS individual's education level, living arrangements, and number of friends reported was similar to those of his or her neurotypical peers with regard to reports on their perceived quality of life. Employment experiences were less positive for AS individuals and they admitted a preference for solitary activities (Jennes-Coussens, Magill-Evans, & Koning, 2006). Most of the participants in a study conducted by Portway and Johnson were unhappy, anxious, and depressed. A few discussed suicide as the ultimate way of opting out of life in general, highlighting the significant risk to long term mental health and the marginal status that they feel (Portway & Johnson, 2005). Suicide is linked to gender and age with the greater incidence among younger men, depression and anxiety, unskilled and unemployed occupational status, low self-esteem, isolation, and poor social integration; lack of problem solving skills are also greater. Many of these risk factors especially apply to males with AS (Portway & Johnson, 2005).

Adult Outcomes

There are few specialized support systems for adults with AS. Most adults with AS rely heavily upon family support to find and maintain employment and housing. With that noted, there is a high degree of variability in the outcomes among individuals with AS. Often their SIA leads them to, or excludes them from, social acceptance. Lorna Wing, who was introduced earlier in this section as the person credited with changing the epidemiology of autistic conditions to the concept of the autism spectrum (Wolff, 2004), wrote that the higher rates of social independence will be achieved by AS individuals that have good self-care, a special ability that can be used in paid employment, and a placid nature.

Areas of concern for adults with AS include employment, comorbid mental and physical health issues, neurological challenges, possible involvement with the legal system, and mortality rates (Barnhill, 2007). Although many parents of AS individuals provide general care including food, shelter, and security, the level of support being provided to these individuals by their family runs much deeper. This includes 24-hour mental commitment, psychological "watching over", providing companionship due to the absence of friendships; structuring the AS adult's daily routines; putting unseen safeguards into place; and creating opportunities for socializing, further education, employment and daily activities (Portway & Johnson, 2005).

Marriage for the AS adult can be a tenuous endeavor. Due to their social deficits and weak theory of mind, central coherences, and executive functioning, it takes a significant amount of work for a neurotypical partner to maintain a satisfying relationship with an AS partner. The neurotypical partner has to understand about the condition and make an informed decision about marrying. Unlike most disabilities, AS is invisible but has a very serious impact on the heart of the relationship. The neurotypical partner will have to make all of the adjustments and will likely be a care giver to the AS partner. It can be a lonely and traumatic state in which to live (Winster, 2004).

Spirituality

Spiritual practice and organized religion can play an important role in helping the AS individual cope with their social difficulties. Meditation and prayer has been shown to enable AS individuals in focusing on a deeper way of developing social/self awareness. The value of being part of a group that accepts the AS individual unconditionally has also been shown to provide great benefits to this population (Muller, Schuler, & Yates, 2008).

Employment

Many individuals with AS have difficulty finding a vocational niche, securing work that is commensurate with their abilities, maintaining their jobs, and successfully negotiating social relationships. Few adults with AS successfully maintain regular employment (Barnhill, 2007). AS individuals require a high level of ongoing support and consideration due to the detrimental effect that failed work placement likely has on their self-esteem (Macleod, 1999).

Violence/Incarceration/Criminal Behaviors

Individuals with AS are overrepresented among inmates of special forensic hospitals (Ghaziuddin, 2002) and are at particular risk to engage in illegal behaviors, especially violence (Woodbury-Smith et al., 2006). There are a number of case reports of violent offending, fire setting, and sexual offending by people with AS (Barry-Walsh & Mullen, 2004). Despite this statement, self-report and "official" data indicate that the rate of law-breaking, including offending, is very low in the AS population as compared to the general population. In fact, due to their often rigid thinking, individuals with AS adhere to lawful behavior more consistently than their general population counterparts (Woodbury-Smith et al., 2006). Crimes committed may be unusual or bizarre in nature (Howlin, 2000). Given the fact that individuals with AS have a relative incapacity to either know or understand how others think and feel, the question must be asked if individuals with AS should be deprived of the expectation of social responsibility due to the nature of their disorder (Barry-Walsh & Mullen, 2004).

Individuals with AS are less likely to engage in illicit drug-taking and more likely to be engaged in categories described as criminal damage. Illegal behaviors are often carried out in response to perceived victimization, feelings of resentment, and feelings of being provoked. Due to the fact that many individuals with AS feel powerless, they may engage in acts that are deliberately intended to cause shock and disruption and are generally characterized as malicious. The individual with AS does not typically view his behavior as a reaction to his social exclusion.

When individual with AS do offend, they are generally prepared to admit their illegal behavior (Woodbury-Smith et al., 2006). Little research has been done on the possibility that people with AS may be related to deficits in social cognition (Baron-Cohen, 1988). Most of the violent and criminal acts that are committed stem from the idiosyncratic preoccupations seen in the AS population. Intense fixations, a key component of AS, can lead to such outcomes. When an individual with AS commits criminal acts, they seldom make an effort to conceal those acts or their motives (Ghaziuddin, 2002). There is no data on alcohol or drug abuse in autism. However, those who are high functioning make strenuous attempts to avoid drugs of any kind, including prescription drugs. Instead, it is more common for these individuals to get themselves into trouble for interfering with people who are smoking or drinking, or even lecturing others on the evils of gang involvement. It should be noted that due to the tendency of AS individuals to be rigid and routine oriented, it would seem that if drug or alcohol habits became established, these behaviors would be very difficult to modify (Howlin, 2000).

Parents with Asperger's Syndrome

Parents with Asperger's Syndrome can exhibit either minor and/or significant problems in parenting. These issues can have a significant impact on child rearing. Problems in parenting are directly related to the core neuro-cognitive clinical features of AS, namely weak central coherence, poor cognitive shifting and lack of a theory of mind (Linehan & Jennings, 2007).

AS parents lack insight into their condition and into the impact of it on their role as a parent. The need for support services is essential since many parents with AS have children with AS, which presents enormous challenges to the parent. AS parents find it difficult to tolerate the normal noise, mess and chaos of childhood, especially with the high pressure needs of special needs children. AS parents often cope by leaving the situation, shutting down, melting down, or withdrawing, thus leaving vulnerable children to fend for themselves (Linehan & Jennings, 2007).

The mind blind parent (Theory of Mind) generally cannot correctly discern the thoughts, wishes, knowledge or intentions of their own child. With regard to the pre-verbal child, this missing core parenting feature could have disastrous outcomes. Secure attachment hinges on the caregiver's sensitivity and response to their child's needs and signals. Some parents with AS suffer from poor impulse control and from autistic rage which may cause them to react strongly to a misunderstood child behavior (Linehan & Jennings, 2007).

Since most AS parents lack central coherence, the ability to focus on both details as well as wholes of a given situation and follow through on plans in a variety of areas, they can lose sight of a situation involving their child and fail to provide appropriate supervision and safety. In conclusion, parents with AS require a great deal of support in their role as a parent (Linehan & Jennings, 2007).

SUMMARY

Autism, first identified in the early 1940s, continues to be a puzzling disorder. Research into the causes and treatment of autism is a growing field. Autism and Asperger's Syndrome are considered Pervasive Developmental Disorders (PDD). Others consider Asperger's Syndrome (AS) in terms of an Autism Spectrum Disorder (Schnur, 2005). One of the unique features of Asperger's Syndrome is the special interest areas (SIA). SIA significantly impact the entire family system and occur in over 90% of children and adults with AS (Winter-Messiers, 2007).

The prevalence of autism has increased over the years from 4-5 per 10,000 to around 6 per 1,000 children (Wolff, 2004). The number of children affected by Asperger's Syndrome doubles the number of children who exhibit classic autism (VanBergeijk, 2005). Debate is ongoing as to whether the increase in diagnosed cases of autism is related to environmental factors or increased medical knowledge (Wolff, 2004). Prevalence rates have increased tenfold in the past decade (VanBergeijk, 2005). No single environmental risk factor has been shown to substantially increase the risk of autism in children (Fombonne, 2003).

Asperger's Syndrome was added to the *Diagnostic and Statistical Manual of Mental Disorders*, 4th Edition (DSM-IV; American Psychiatric Association, 2000). The

DSM-IV makes the distinction between autism and AS solely on the basis of the onset criteria (Klin et al., 2005). AS is also defined in the International Statistical Classification of Diseases, Tenth Edition (ICD-10) and was added in 1990 (VenBergeijk, 2005). Autism has a strong association with seizures and mental retardation (Fombonne, 2003), speech and language disorders, and hearing and visual impairments (Gillberg and Billstedt, 2000). The onset of epilepsy in autism often occurs in adolescence or early adulthood and its incidence is between 18-20% (Howlan, 2000).

Comorbidity is often the rule rather than the exception in AS (Ghaziuddin, 2002). Studies have found that there is an excess of mood and anxiety disorders in the parents of individuals with autism (Ghaziuddin, 2005). Parents of children with AS are challenged greatly by the uneven development of their children and are at increased risk of developing psychological difficulties (Pakenham, Sofronoff, & Samios, 2004).

In the 1970s, experimental studies showed that developmental gains could be achieved in children with autism. Autistic children benefited most when home and classroom environments were structured to capitalize on their individual strengths and compensate for their deficits, when the classroom offered a high teacher to pupil ratio with individual educational plans (IEP), and when parents acted as co therapists to promote the child's generalization of learning (Fombonne, 2003).

Treatment and support of AS individuals can take many forms. There is little evidence-based information about pharmacological treatments of individuals with AS (Tsai, 2007). Concepts such as Theory of Mind (Jacobsen, 2004), Central coherence (Jacobsen, 2004), and executive functioning issues play a big role in the life of the AS individual. Therapeutic intervention must address awareness of this deficit in the AS individual (Jacobsen, 2004). Many and varied therapeutic models have been utilized to work with AS individuals. No two individuals with AS are alike thus indicating that creative measures must be used to tailor treatment plans to each affected individual's specific strengths and deficits (VanBergeijk, 2005). Since children with AS show serious interactive impairments, the siblings of these children are frequently exposed to multiple behavioral and social maladjustment problems in their family environment (Dellve et al., 1999). Autism ranks among the most stressful challenges to a family with regard to developmental disabilities. Problems with communication, emotional expression and antisocial behaviors, all combined place tremendous stress on the family (Gray, 2006). According to the US Census Bureau, approximately 16% of marriages end in divorce prior to the couple's fifth anniversary, 35% prior to the 10th tenth anniversary, and 48% prior to the 15th anniversary (http://www.divorcemag.com/statistics/statsUS.shtml,2008, accessed, 09/28/2008).

Social dysfunction might be the single most handicapping feature of AS (Carrington, Templeton, & Papinczak, 2003). Due to their unusual mannerisms, view of the world, and social deficits, individuals with AS are often targets of victimization and bullying. Prevalence rates reported by mothers of AS children was 94% in a study conducted by Little in 2001. Clarification of etiology could help with prenatal diagnosis and genetic counseling as well as understanding of what, if any, environmental triggers may be in relationship to the development of AS. Many screening tests exist to identify Asperger's Syndrome.

It can be argued that life's course is shaped by levels of influence imposed through the interplay among the individual, family, school, peers, and community factors. One of the most significant impacts on a child's life course is his own participation through the course of everyday activities and through ongoing interactions with others. The primary objective for the family of an individual with AS is to set up a supportive family environment and a responsive educational environment (Gable, 2005).

There are few specialized support systems for adults with AS. Most rely heavily upon the support of their families to find employment and housing. There is a high degree of variability in the outcomes among individuals with AS. Often their SIA leads them to, or excludes them from, social acceptance. Areas of concern for adults with AS include employment, co-morbid mental and physical health issues, neurological challenges, possible involvement with the legal system, and mortality rates (Barnhill, 2007). Spiritual practice and organized religion can play in important role in helping the AS individual cope with their social difficulties (Muller, Schuler, & Yates, 2008).

Few adults with AS successfully maintain regular employment (Barnhill, 2007). AS individuals require a high level of ongoing support and consideration due to the detrimental effect that failed work placement likely has on their self-esteem (Macleod, 1999).

Individuals with AS are overrepresented among forensic hospitals (Ghaziuddin, 2002) and are at particular risk to engage in illegal behaviors, especially violence (Woodbury-Smith et al., 2006). Despite this, data indicates that the rate of law-breaking, including offending, is very low in the AS population as compared to the general population. Due to their often rigid thinking, individuals with AS adhere to lawful behavior more consistently than their general population counterparts (Woodbury-Smith et al., 2006).

Parents with Asperger's Syndrome can exhibit either minor and/or significant problems in parenting. These issues can have a significant impact on child rearing. Problems in parenting are directly related to the core neuro-cognitive clinical features of AS, namely weak central coherence, poor cognitive shifting and lack of a theory of mind (Linehan & Jennings, 2007).

There is much to be learned about the factors that impact not only the individual with AS but how the entire family system is impacted by this disability. Despite the growing amount of literature on the etiology, causes, and treatment of the individual with AS, there is little research devoted to the impact that AS has on the family system. It is the goal of this research project to explore how AS impacts the family system. I will explore both the challenges and joys that families living with this disability face. It is hoped that the information gleaned from this project will help to strengthen the knowledge base of professionals working with families impacted by AS. With greater understanding into the dynamics of the family system living with AS, it is further the goal of this research project to increase and enhance support services for both the individual and family living with AS which in turn will foster increased positive outcomes for all.

CHAPTER III

METHODOLOGY

METHOD

This study investigated the impact of living with Asperger's Syndrome on the entire family system by studying the perceptions and experiences of family members. A qualitative research approach was employed. Qualitative research methods tap into the deeper meaning of particular human experiences and generate rich observations that are not easily reduced to numbers. Qualitative studies permit the use of subjectivity to generate deeper understanding of the meanings of the human experience (Rubin & Babbie, 2007). This chapter provides an explanation of the study design, selection of participants for the study, the procedure that was followed, how participant's rights were protected, a description of the materials that were used in the study, and the methods used for data collection and data analysis.

DESIGN

A life story research design was employed to better understand the experiences of these families. The person-in-environment approach is fundamental to the practice of social work and fit nicely with the life story approach. In working with families affected by Asperger's Syndrome, social workers need to understand how family members and the entire family system perceive the impact of living with the disability and thereby include them in the plan of care. To effectively include family members in caring for those with Asperger's Syndrome, it is essential for social workers to learn more about the experiences and perceptions of family members living with this form of autism.

> The life story or life history approach is a method that emphasizes qualitative interviewing with the use of open-ended questions to discover how the participants in the study understand the significant events and meaning in their own lives. Researchers employing this method attempt to see how the individual subjectively remembers and understands the significant events of their lives. (Rubin & Babbie, 2007, p 239)

There is great power in the use of the life story paradigm. Life stories are more than books that people read or share. The life story represents a pattern, a way of organizing and sharing individual experiences and realities. Life stories are actual stories that are happening in the real world, all around us, all of the time. Learning about the life stories of others, thinking about our own life stories, and discovering how these stories intersect (who or what is in the foreground and background of each other's life stories) provides the guidance we need to effectively enhance the lives of others (http://www.co-intelligence.org/I-powerofstory.html, accessed 12/24/08). Thus, the research question for this study was:"What impact does Asperger's Syndrome have on the family?'

PARTICIPANTS

According to Heppner and Heppner (2004),"when no new themes or patterns become apparent, when no additional information is forthcoming, sample selection and date collection may end" (p. 156). In qualitative research studies, it is difficult to predict the exact number of participants needed prior to the onset of a study. Just as every family system is unique, so is each family's experience with Asperger's Syndrome. A small, yet representative sample of participants was obtained. Six in-depth interviews were conducted.

Participants were identified using purposeful sampling. Rubin and Babbie (2007) define purposive sampling as selecting a sample of observations or participants that the researcher believes will yield the most comprehensive understanding of the subject of study, based on the researcher's intuitive feel for the subject that forms from extended observations and reflection.

Participants of this study were parents of children diagnosed with Asperger's Syndrome. Participants included both biological and adoptive parents of individuals diagnosed with Asperger's Syndrome. Participants volunteered for the study based upon their interest in sharing their story with the researcher.

Participants were located through word of mouth and via an open letter (Appendix) made available at the following community events: an ARC (Association for Retarded Citizens) sponsored Autism Fair held in St Cloud, Minnesota on September 28, 2008, a MNASAP (Minnesota Adoption Support and Preservation Organization) event held in St. Cloud, Minnesota on October 4, 2008, a Family Fun Day community event sponsored by STARS (System Transformation of Area Resources and Services) for a Children's Mental Health event held in Monticello, Minnesota on October 11, 2008. STARS (System Transformation of Area Resources and Services) is an organization that is funded through a grant from the federal SAMSHA (Substance Abuse and Mental Health Services Administration) commission and provides services to the four county area of Benton, Sherburne, Stearns, and Wright Counties in Minnesota. The ARC and STARS events were free and open to the community while the MNASAP event was an enrollment fee event.

Representatives of the sponsoring agencies and programs were informed of the study. Prior permission was obtained from event organizers to seek volunteers for the study during these events. Additionally, the open letter was also picked up and circulated by area educators, professionals, and family members who chose to disperse it to family members, neighbors, friends, and acquaintances that they thought might be interested.

These event dates pre-date the preliminary thesis committee approval meeting (12/05/08) and the Institutional Review Board (IRB) approval date (12/30/08) of this project. I felt that in order to identify and find the target population needed for this project, it was imperative that contacts to be made at the above noted community events. Discussion was held with the chair of the thesis committee and verbal approval to circulate the letter for respondents was granted. The letter was pre-approved by the thesis committee chair for use as well. No other contact with potential respondents was made prior to the approval dates of this project.

Interested individuals contacted me by e-mail or telephone to schedule a time and place to be interviewed. Verbal consent was initially obtained when I consulted with the potential participant to describe the study and the goals of the research. Subsequent written informed consent was obtained prior to the formal interview process (Appendix).

In order to be included in the study, the participant had to meet the following criteria: (a) have a family member formally diagnosed with Asperger's Syndrome or related diagnosis of Autism or PDD-NOS with an I.Q. above 70, (b) be able to speak and understand English, (c) be 18 years of age or older, (d) have an identified child over the age of 7, (e) agree to have their comments digitally-recorded, (f) agree to participate in the study, and (g) agree to share their experiences and perceptions of their family situation.

Thirteen families contacted me expressing an interest in participating in the project. Two of the families did not return my calls, two failed to appear for the scheduled interviews, two had children with I.Q.s below 70, and one had a child under age 7.

I am acquainted with many individuals who have a child or family member diagnosed with an autism spectrum disorder, and many individuals who are diagnosed with Asperger's Syndrome. It was preferred that families unknown to me were interviewed and that the family member be specifically diagnosed with Asperger's Syndrome. Diagnostic determinations on the definitive diagnoses of Asperger's Syndrome, PDD-NOS, and High Functioning Autism are extremely subjective and chosen based upon DSM-IV criterion through subjective measures by the diagnosing professional. Because of this, although it was preferred that only family's living with a member diagnosed with Asperger's Syndrome be interviewed, one participating family who was interviewed had a child diagnosed with Autism with an I.Q. of 71.

Of the six families interviewed, one family was known to me. Six women and five men were interviewed. All couples were married; one of the husbands was unable to participate in the study due to his work schedule. Although children were not interviewed, in most cases the families introduced their child to me, along with any other siblings that happened to be home at the time of the interview. I did not ask any research-related questions of the children. The five boys and one girl with an ASD diagnosis ranged in age from 7 to 16. Five of the children had diagnoses of Asperger's Syndrome and one had a diagnosis of Autism. Five of the children were biological children and one was an adopted child. The children's intellectual functioning levels differed greatly from borderline intellectual functioning to very high I.Q.s. A comprehensive description of participant demographics can be found in Table 2.

PROCEDURES

All interviews were conducted in mutually agreed-upon locations. For families with both parents participating, the interview was conducted with all participants engaged in the interview at the same time with me. Two interviews were held in coffee shops and four were held in the home of the family being interviewed. The locations were chosen by the participants with the goal of being convenient and allowing for the protection of privacy. Interviews generally lasted between 1 and 2 hours.

PROTECTION OF HUMAN RIGHTS

To protect human rights, the Institutional Review Board (IRB) of St. Cloud State University approved this study. Verbal permission and a written consent (Appendix) were obtained from each of the 11 adults interviewed. The participants were informed that their involvement in the study was voluntary and that they could withdraw their participation at any time without consequences. I provided each participant with written and verbal informed consent paperwork along with a copy of the IRB approval letter. Signatures of consent were obtained from each participant. Each participant was given an opportunity to ask questions regarding the study and their involvement in the study and offered a copy of the final project upon its completion. Through the course of the interview, when it appeared that a participant was in need of additional support or was experiencing extreme distress due to their situation, I provided resource materials to the participants of existing support resource options and agencies. Four of the women and two of the men cried while talking about their stories.

To preserve the participant's confidentiality, identifying information is not in field notes or other documentation that could be connected to the participant. I followed the guidelines and regulations for human participant research, as defined by St. Cloud State's IRB in order to protect the rights of the participants in this study. The audiotapes, transcripts, and information sheets are kept in a password protected file located in my home and on my home computer. Only I, my transcriptionist, and my thesis committee have had access to the information as needed for writing the report, verifying information, and/or clarifying questions about the data. Once the project is completed and approved, the data will be shredded, deleted, and destroyed.

As stated earlier, the participants' names do not appear on the transcripts or field notes. I assigned pseudonyms to each of the participants to preserve anonymity. To ensure accuracy and clarity of the participants' responses, I clarified the participants' responses while the interview was in progress. No follow up has been needed. In the event that follow up is necessary, a master list of numbers assigned to interviewees was kept on file during the course of the project.

LIMITATIONS AND BENEFITS

Generalizability is an issue when using purposive sampling and in qualitative research. Limitations include the fact that the sample will be limited to Minnesotans, English speaking individuals, families who may or may not already be involved in and receiving services (which can skew their perceptions), those who are likely to be willing to share their stories (which might exclude shy) and lower-functioning individuals. It is hoped that despite these limitations, the themes that emerged will shed light on potential strategies that can improve upon services, supports, and interventions for all family systems living with Asperger's Syndrome.

Knowledge about this population is extremely important because family members are frequently the disabled individual's primary, and often only, support. The research data obtained from this study, and further research in this area, could be beneficial if applied to the practice of all helping professions, including social work. Applying this knowledge to practice could facilitate better services for all those impacted by Asperger's Syndrome.

INSTRUMENTS

One of the techniques used in qualitative research is to obtain data through open-ended questions. One primary open-ended question was asked of participants,"Can you tell me your story about what it is like living in a family affected by Asperger's Syndrome and how it has affected your family system?" This open-ended question was asked of each participant so that he or she could provide his/her own unique answer.

Expansion of this answer was guided through informal use of the *Caregiver Strain Index* (CSI) (http://medschool.ucsf.edu/sfghres/fhc/pdf/Caregiver_strain.pdf, accessed, 11/11/2008). The CSI is a 13-question tool that measures strain related to care provision. There is at least one item for each of the major domains: employment, financial, physical, social, and time. Positive responses to seven or more items on the index indicate a level of strain that may indicate a need for more in-depth assessment to facilitate appropriate intervention. The use of the CSI was used to enhance the feedback received from the participants during the interview. The CSI was not used as a formal testing tool. If the items on the tool were not naturally addressed or identified during the course of the interview, I asked the questions identified in the tool when necessary to ensure that the concepts were addressed.

This instrument can be used to assess individuals of any age who are in the role of caregiver. It was developed with a sample of 132 caregivers providing assistance to recently hospitalized older adults. Internal consistency reliability is high (alpha = 0.86) and construct validity is supported by correlations with the physical and emotional health of the caregiver and with subjective views of the caregiving situation (http://medschool.ucsf.edu/sfghres/fhc/pdf/Caregiver_strain.pdf, accessed 11/11/2008) (see Table).

DATA COLLECTION

Prior to my gathering data from the participants, it was essential for me to set aside any preconceived ideas or biases related to the research topic. This was especially important due to the fact that I am the parent of a child diagnosed with Asperger's Syndrome. Based upon my own experiences, and prior to initiating this study, I believed that Asperger's Syndrome has a significant impact on the quality of life for each member of the family, and the family as a system, as well as the individual living with Asperger's Syndrome. I believe that service-oriented professionals frequently forget about addressing this aspect when developing the care plan for the disabled individual.

The opening question for each interview was, "Can you tell me your story about what it is like living in a family affected by Asperger's Syndrome and how it has affected your family system?" Each participant was informed that their involvement consisted of a one-time interview. Each interview was comprised of open-ended questions and approximately 60-90 minutes in length. With verbal consent from the participant, the interview was digitally taped. I had each of the taped interviews transcribed. For all of the participants, prior to starting the formal portion of the interview, the researcher gathered demographic information. Demographic information obtained included age, sex, race, marital status, education level, employment status, relation to child, diagnosis of family member, length of time family member has had the diagnosis and their role in caring for the family member.

I reached for expansion of issues, using questions from the CSI tool as needed. Both verbal and non-verbal prompts were used including,“uh-huh,”“I see,”“oh,”“um,”,“Can you tell me more about that?”,“What was that like for you?”,“Can you tell about a time when that happened?”, and so forth, to encourage conversation. These probes encouraged and prompted the participant to provide further descriptions of their experiences and perceptions. This approach also helped to provide direction and focus to the interaction. The interview proceeded and focused on the primary research question.

DATA ANALYSIS

The life story method looks for patterns, themes, or common categories in analyzing the data obtained. It is an inductive research approach that attempts to generate theories from the constant comparison of unfolding observations. This approach, drawing from grounded theory, allows a great deal of latitude for the discovery of unexpected and expected hypothesis (Rubin & Babbie, 2007).

Theme identification is one of the most fundamental tasks in qualitative research and also one of the most mysterious. Descriptions of theme discovery are seldom described in articles and reports and if so are often buried in the appendices or footnotes. It is difficult to clearly explain and justify plans for discovering themes.

http://www.analytictech.com/mb870/Readings/ryan-bernard_techniques_to_identify_themes_in.htm (accessed 12/24/08).

Themes were identified using the following techniques: the characteristics of the phenomena being studied, already-agreed-upon professional definitions, local common-sense constructs, and my values, theoretical orientation, and personal experience with the subject matter. Techniques that were used for discovering themes were based upon: (1) an analysis of words (word repetitions, key-indigenous terms, and key-words-in contexts); (2) carefully reading larger blocks of texts (compare and contrast, social science queries, and searching for missing information); (3) intentional analysis of linguistic features (metaphors, transitions, connectors); and (4) the physical manipulation of texts (unmarked texts, pawing, and cut and sort procedures) (http://www.analytictech.com/mb870/Readings/ryan-bernard_techniques_to_identify_themes_in.htm, accessed 12/24/08). Techniques used for discovering the specific themes that emerged in the data included line by line review of the transcriptions, breaking the information down into major themes and then breaking the themes down within the major themes into more specific themes. After this was done, I used the framework of the micro, messo, and macro levels of systems to further categorize and define the themes which emerged from the data.

The interviews were transcribed verbatim by a colleague of mine and analyzed solely by me. My transcriptionist was not given identifying information about the participants in the study and was reminded of the expectations of confidentiality related to the material.

It is important to point out that the themes identified are only part of the complete experience of living in a family affected by Asperger's Syndrome, the portion of the experience being studied. Commonalities identified between and among the families interviewed led to the development of themes within the family stories. Learning from the participants the meaning of their experiences is valuable and relevant because a true understanding in the meaning of the experience can only be obtained from someone who is actually living in the experience. Each experience is unique and can only serve to enrich what is known or not known about the experience. Findings obtained should help develop concepts which can lead to an overall improvement in services, interventions, and outcomes for all involved.

Chapter IV

DATA RESULTS AND ANALYSIS

What is it like to live in a family affected by Asperger's Syndrome? How is each member of the family individually, and as a system, impacted by the experience? How did the parents interviewed describe their experiences? In this chapter, I will report the results of this study based on an analysis of the stories told by the 11 research participants. I illustrate the major themes that emerged using quotations from the data collected. Data was collected between December of 2008 and February of 2009.

OVERVIEW

The purpose of this study was to investigate the impact that living with Asperger's Syndrome has on the entire family system. This was accomplished by studying the perceptions and experiences of family members through an interview process by using a qualitative research design focusing on the life story method of data collection. Participants in this study were very excited to participate in the research and interested in receiving a copy of the study. I began each interview by having the participants read and sign informed consent paperwork. One copy was given to the participants and one was kept by this researcher. A short demographic questionnaire, described in Chapter III, was then completed. Following this, I used the same essential phrase to launch the conversation.

> I don't have any specific questions to ask. I will be using a tool called the caregiver strain tool which helps rate the strain a person feels when caring for a loved one's special needs. I will be using this tool as a guide to ensure that we address topics such as the time it takes to care for your love one; the emotional strain this care giving places on your other relationships, etc. I just want to have a conversation. I'm interested to hear about how you identified that something was different about your child and how you learned about Asperger's Syndrome. I want to hear about the whole process of identifying and naming the disability as well as how it has affected your family.

Going into this study as a researcher posed special challenges to me. As a parent of a child with Asperger's Syndrome, it was essential that I entered into each interview with a clear mind and the proverbial blank slate with no agenda or idea of what I might learn. I did this by focusing my attention on the stories I was hearing and putting aside my own stories or thoughts on the subject. I wanted to document accurate information and to represent the life stories I heard in the most neutral manner possible. I wanted the participants to feel comfortable with sharing their feelings and perceptions about their experiences in parenting their special needs child. Therefore, I felt it was important to make it clear to each interviewee that I had several years of experience in working with families, special needs children, and conducting non-judgmental interviews. Each participant welcomed me into their life story and was eager to share their thoughts, struggles, and perceptions related to those stories. They were pleased to have someone show an interest in hearing their story, have an opportunity to vent, and know that the person listening to them had an understanding of the road on which they were traveling.

One thing that really stood out was the passion with which each participant talked about their child. Despite the challenges, struggles, joys, and stresses, it was clear that each of the participants in this study were completely invested in their child because of, in spite of, or as a result of that child being a part of their family system.

To make sense of the data collected, I read and reread all of my transcribed notes several times in search of common themes and patterns. As I searched for themes and patterns, I made lists and sub lists. I created headings and subheadings using color coding in order to further break down and identify potential themes. In order to identify themes, I looked at the number of times the same subject was identified and the level of emotion in which the subject was expressed. I also considered the circumstances that surrounded the identified subject, how many times the person being interviewed returned to the same particular subject, and again the level of emotion that surrounded that subject.

Each interview was analyzed using the same method of categorization, and data was coded in the same way between each interview. Once I had a list of approximately twenty potential themes, I went back to my transcriptions and assigned a color to each interview. I then copied sections of the interviews into the different identified thematic areas. Once I completed this, I reviewed the list of possible themes and grouped them into thematic subjects. I then sent my lists to my committee members for feedback and suggestions.

Each major theme is identified within its own section. It was challenging to narrow down the data to specific themes throughout the analysis process. Each interview was emotion laden and heartfelt. Each and every statement carried a tremendous amount of meaning to the journey in which these individuals live their lives. In order to support a smooth flowing chapter, instead of identifying the parents interviewed by Mom 1, Dad 2, Mom 3, etc., each parent has been given a pseudonym.

Although major themes are identified and are discussed in separate sections, the themes have overlapping qualities. Seven major themes were identified. *Why is Junior so Odd?, What Kind of Help Should I Access and Where Do I Find It?, This is Not What I Expected, Relationships are Challenging, Problems with Peers, The School Experience, and It Is What It Is: Living with Atypical Behaviors.* These themes were placed in this specific order because they follow the natural progression of life. As much as possible, I have used the participants' own words to name the themes that emerged.

Why is Junior so Odd focuses on those initial identifications made by parents that their child seemed to be developing differently from his/her neurotypically developing peers. *What Kind of Help Should I Access and Where Do I Find It* was a common theme identified by each of the families interviewed. As these families moved into the preschool years with their child, and watched the developmental and social gap broaden between their child and other children, it became increasingly clear to them, by their report, of the importance that they seek out help and support for their child and to some extent for themselves and their entire family system. *This is Not What I Expected* describes how the families interviewed defined their story about the initial impact that having a child with a disability played on the family's life script. *Relationships are Challenging* describes the complexities that these families experienced with regard to relationships with extended family, friends, and the community. This theme is also related to the role that relationships have played on the family's needs for support and acceptance in their daily lives as reported by all of the families interviewed. *Problems with Peers* describes the experiences, reported by each of the families, of the impact of the problems that occur between the disabled child and his/her peer group on the family system. *The School Experience* explains the significant impact that school plays on the family's functioning. Each family had a number of stories related to the difficulties that school interactions have caused for their child and the impact it has had on their family stress levels. *It Is What It Is: Living with Atypical Behaviors* focuses on the adjustments made by the family and the efforts towards homeostasis that have occurred. One of the mothers interviewed used the exact phrase, "It is what it is!" I, myself, came to that conclusion years ago and embrace that philosophy regarding my own family situation. I will now discuss each theme in detail by giving examples from the participants' individual interview responses, and from my observations during the interview process.

THEME 1: WHY IS JUNIOR SO ODD?

As a parent, I believe that despite our best efforts in preparing for parenthood, raising children is a mystery. No guidebook or clear set of guidelines accompanies the birth or adoption of a child. Parents do the best job they know how to do. We all have expectations of what our child will be like, how he/she will act, and what he/she will become. Although it is impossible to identify what is normal, the general expectation is that a child will provide reciprocal feedback and affection in response to his/her parent's efforts, talk in the second year of life, and progress along a typical plane of development.

As reported in all of the interviews, each participant had something to say about this theme. Ann described her recognition of her son's differences in the following excerpt:

> I kind of noticed it earlier, because my mom was a special education teacher and she lived with us at the time, and his development wasn't progressing. The first thing now that I think back, he was crawling and almost walking before he could sit upright and stay up right. So there was that like that chunk there that never developed or hadn't. Well now that I know a little bit more about Asperger's they are slouchers. They like curled up. Now that I think about it that was something right away that I wouldn't have noticed but now thinking back I go through the mental check list and ok that and it took a him a long time to get the concept of potty training, but once it all came together, boom, that was it. Those were the first things that I noticed.

Like Ann, Sara also noticed early signs of the differences in development of her son that may have been early indicators of Asperger's syndrome.

> He was 2 months shy of 3 and they diagnosed him with Autism, because he wasn't talking. If I look back on some of his baby stuff I can see that he was saying some things. He was saying bye, mom, dad, please, a few words were sign language. He was starting to talk and then all of a sudden he wasn't saying anything. It wasn't like he was talking a lot and then not saying anything. He would say a few words but then nothing....I see the other kids. They are talking. My big turning point they gave me some evaluation form afterward and they started doing speech and they said he tested abnormal for registration....I started putting things together. The sensory issues. He hated having his teeth brushed. He hated having his hair cut. Hated it. He would only drink chocolate milk and he wouldn't drink other kind of milk. When he was first not talking very much, he called chocolate milk, bom mow. Tree was ah bah. It wasn't even normal.

Sara further spoke about her challenges with potty training her son and how she finally found a doctor who would acknowledge her concerns.

> Everybody was all worried about getting their kid potty trained and I was just worrying about my kid talking......what happened was at the doctor who was going to put the stethoscope on him, and Billy freaked out. And the doctors like, ummmm, and I could tell the doctors like crap; I got to say something to this lady. Here she is coming in for her son who's sick, and I said you are concerned about his reactions aren't you? And I said I am too. I have questions about that. Now the

> doctor looked relieved because I don't have to tell her something that she already suspected.

For Grace, she noticed little things that seemed odd about her child that began to worry her about his development. Here is an example of her report, "When he was 2 we started noticing things that were just little red flags. I would talk to the pediatrician about it, and she says we'll keep monitoring. I just want to make sure that you are keeping it in the record that we are noticing little things." For Steve, his identification of his child's differences were also gradual. Some of his comments included a description of how his son played and interacted with other children such as, "He didn't talk outside of us. He didn't socialize with anybody. He played by himself fine for hours. He wouldn't play with other kids or other adults."

Some of the families interviewed couldn't quite put their finger on what was going on with their child. "Bobby was 4 when we took him in to be checked. Up to that point, we just kind of thought that we were raising the most stubborn man in existence." Erin went on to talk about how set in his ways her son was. "I had to do everything for him. If you surprised him, he could come out with a full sentence, otherwise he didn't talk." Although Erin seemed to have an idea that something was different about her son, but was not quite sure what that difference was, Rose had no idea that her son was different until she witnessed his first meltdown, shared in this excerpt:

> As far as I'm concerned he was absolutely perfect, so it never really entered my mind, but there were, when he was 2, we had him down for his nap..... something happened and we had a bit of a flood...brought carpet shampooer.....to extract the water out of the rug.... started doing his thing.... and....Johnny....was absolutely losing it.

Identifying the child as different or not developing as expected was clear to some of the parents interviewed while a learning process for others. Grace described her daughter as:

> ...very flat affected. Usually babies are expressive, and she was very flat, almost kind of snobby. She would kind of look at you, whatever. If you can imagine a baby. We discounted it because our adoption agency followed up with her afterward, and it seemed a little odd...

For Steve, he only began to really notice the differences in his first child when his second child entered the family.

> Me on the other hand.... being a first time parent........I guess I didn't really notice anything with Susie other than I think that as she got closer to 2, I started noticing the lack of emotion she would show. Maybe that was something. To me, it really became profound, after we adopted Sally. You could see the difference between; I don't like to say it, but a normal kid.

Grace acknowledges what many of the other parents interviewed for this study also identified in their remarks,".....it was just like an aching feeling something is weird here, but you didn't have anything to grasp it to." The above excerpts identify that each participant in this study recognized that their child was developing differently from his/her neurotypical peers but did not necessarily know what to do with those observations. Many commonalities were found among the families interviewed as evidenced by the above excerpts.

THEME 2: WHAT KIND OF HELP SHOULD I ACCESS AND WHERE DO I FIND IT?

Most of the families interviewed described the emotions they felt as they discovered that their child was developing differently from typical children. The families interviewed for this study reported how the experience of watching their child's different development from his/her peers were heart wrenching and overwhelming. Most of the families reported that once they were able to accept the diagnosis, they were ready to move forward in accessing the resources and services needed to help their child and family reach the highest potential possible. Some participants that were involved in this study recognized that their child was different but did not feel that those differences were cause for concern or were cause for accessing services.

Becoming aware and familiar with the supports and services available can be a challenging undertaking. In the following example, Ann shares some of her experiences on this subject."I am still getting to know the programs that are available, that is why I went to the autism spectrum fair....A lot of it we learned on our own. A lot of what we learned with dealing with professionals at Pleasantview, internet, autism for dummies...." When questioned about utilizing services for her child, Rose said:"I don't even know what's out there."

Sometimes, it was reported easier to educate oneself on understanding the needs of the child by learning about the disability from others, as described by Ed:"I spent 6 months online playing war with a guy that was self diagnosed Asperger's. I had to find out about it to see what he was talking about."Ed went on to address his feelings about his child. He indicated a passionate attitude espousing the fact that just because his child was different, did not necessarily mean that there was cause for concern:

> Fitting in seamlessly has never been anything that has been important to us at all, so it wasn't a big deal. Oh my god, we have to do something about it. So he doesn't fit in, we need to make sure that he knows how not to fit in. To live this life happily without worrying about oh my god am I going to be the most popular kid in school. It doesn't matter..... We had a lot of help from Pleasantview School in Sauk Rapids. Once they figured out what was going on, then they put the programs in place, where things that can help him that aren't going to let him just game the system, because he is smart as hell. I mean he's, I mean he would game the system if he could, but he knows that we know that.

Many of the parents interviewed in this study had experienced services with different levels of success. Sara reported the following: "We had four PCAs (Personal Care Assistants) I found them myself. I thought they would help. We were never satisfied with that." Sara also reported that sometimes services are not what were expected, were inadequate, or discontinued. Sara talked about this in the following excerpt. "The last couple of years when public health nurse came out, it was like we were down to 15 hours a week, it wasn't a lot...We used to have a social worker, but when he was diagnosed with Asperger's, she said she couldn't come out anymore."

For some parents, having the diagnosis empowered them and supplied them with strength to advocate for their child's needs according to Erin. "It was a relief almost just to know. I felt bad because I'm thinking how is this going to affect him for the rest of his life, but I also felt a relief that now that we know what it is, now we can attack it head on." Here Erin has discussed the personalization that often occurs to a parent when their child has difficulties. She goes on to talk about how services were helpful, but again ended for her child and family. David and Erin also added to the loss of services that their family faced in the following excerpt,"(Researcher) Have you ever worked with a social worker with the county or anything? (David): Yeah. We miss that. (Researcher): Why did you end that? (Erin): When he moved back home, things were going so well, we didn't need services. There again, there's not much they can do. If he's not going to work with the Para, or whatever, there's not much that we can get for help."

Most of the families expressed their emotions in terms of meeting the needs of their child adequately and finding the supports they need in which to accomplish this goal. Erin had much to say about dealing with her challenges.

> It's a big enough dish when you find out your child has Autism, especially if you don't know anything about Autism, like we didn't. Every autistic kid is so different, you still don't know what to expect. Each kid is different. I had a social worker ask me one time how I manage to keep going. I told her god and Prozac. That's pretty much it when you are facing a situation like that. You just do the best you can and get through it.

Realizing that help is needed and planning for the future were also topics addressed by most of the families interviewed. Grace talks about realizing that help was needed."What the heck. It made me very concerned. Oh my gosh, what is going on? Is it at the daycare center, is it at school? We couldn't find any way signs of her being mistreated in any form.... After she shoved me, we can't do this. We need to get some help." She and Steve also talked about the realization that long term planning may be a reality for their family.

> (Grace) We know that she cannot live on her own. She cannot keep living with us. We need to keep living and advancing too. (Steve) That's where I struggle a lot too, because I don't know. I'm starting to look more into the Minnesota Autistic Society. In all honesty, we haven't really looked at them as a major resource. (Grace) But the hard part is that they are still focusing so much on Autism, not

> Asperger's. For us, with that, and then with the fact of the mental retardation part, puts us totally in a whole different area.

Support group opportunities were also identified by the families interviewed in this study. Grace reported the following, "I tried and the parents that are there are kids that have Autism, not Asperger's. It's all the younger kids, even if they are getting older, they have had the Autism since the age 3." Steve added the following, "What's frustrated us, we went locally for a while, we were frustrated with the parents, and I understand it, but all they did was hammer on the system, what was wrong with it. There were no solutions."

Accessing, finding, and maintaining services has proven to be a challenge added to the complicated dimensions of caring for the child with Asperger's Syndrome. From not knowing what services exist, finding the correct questions to ask, and maintaining support services during these fiscally challenging times, each of the families interviewed expressed a continued desire to receive help and support in meeting the unique needs of their special children.

THEME 3: THIS IS NOT WHAT I EXPECTED

In all of the interviews, each of the parents reported that they had not expected to be parenting a child with Asperger's Syndrome. I bring you back to our two little girls in Chapter I who were playing at the park and dreaming about their future lives. "When I grow up I want to be a mom." Who of us would say, "When I grow up I want my child to dictate my career, be unable to read social cues, have tantrums if his socks don't feel quite right, and refuse to be hugged by his grandmother"? What we expect from our preconceived life stories is rarely what we get. The following excerpts portray the unique challenges faced by families living with Asperger's Syndrome.

Ed talks about how work responsibilities have been impacted by having a child with Asperger's Syndrome and some of the challenges it has caused."We had some relationship problems.......scheduling issues with our requirements so that someone was with Freddy. Work wanted both of us there.....one of us needs to be home with our child. We can't both be here. We got through that."

Another significant piece of information identified by the parents in the study related to the social deficits that children with Asperger's Syndrome present in day-to-day living. Ann talks about the social deficits that her AS child displays in this excerpt,"His inability....in recognizing verbal cues, he doesn't pick up that someone is bored with the conversation, or that the conversation is done, or that someone else wants to say something or interject something, that conversations aren't just one sided."

Missing social cues also impacts the literal traits common with an AS individual. Most of the families had examples of the challenges and adjustments need when living with a literal information processor. Sara shared a good example of this in the following excerpt,"....we were like here wash yourself....we had to tell him, close your eyes first, then wash your eyes. He said that hurts, we said shut your eyes. We had to say you are washing your eyelids, not your eyes!'

Making changes to the preferred lifestyle of the family can certainly lead to frustration for the entire family. Most of the parents interviewed for this study shared the feelings they have experienced regarding the need to adjust their expectations for their AS child and the impact it has had on their family life.

> (Sara) ....things take so much longer. We have simplified their life.........we don't make a lot of big plans. We don't go and get real busy. It's just easier that way...... I had to slow way down. I think that has contributed to frustration for us. It's hard to say our life is going to be different than we expected. We are not going to have that....... So then you get burnt out pretty easy and stuff....it's kind of been a little bit nice to have these different schedules because when he is home he can do whatever, and when I'm home I do whatever.

> (Grace) If we wouldn't have been fortunate enough to have an early diagnosis, because had we been struggling with this.......had it not been diagnosed, and taken care of, I don't know how we would have held together.

> (Erin) Time and attention and finances, and it really is a 24 hour job, even though now he is 16... this part time job...probably what saved my sanity.... I had a break. I used to go to work and rest. It was that kind of thing. That's what kept me going......He ended up going to Opportunity Manor (foster care). Yeah. The first 6 months he as there, we slept all the time. We were so exhausted; so emotionally worn out from trying to deal with him. They were able to help him in ways that we couldn't....it just sucks the energy out of the people around them.

For David, his primary coping to handle his frustration was honestly disclosed with the following statement, "I go get a drink."

As families move through the different stages of the family life cycle and start considering the future, long term planning for themselves and their AS child can become a serious consideration. Some of the families expressed a belief that their AS child may be able to live independently while others were not sure of that possibility. Erin discussed her thoughts on this in the following excerpt, "He is going to have guardianship. I think he will have to live in one of those homes as an adult. I don't think we can do it as we get older."

It is true that the challenges in raising a child with Asperger's Syndrome are many, but there are also positive factors that most of the families were able to identify. One example of this is shared by Erin in the following excerpt," .....he has really taught you to look for more behind people's behaviors. I hear things about crimes or kids getting in trouble....and I'm thinking that there is more behind it...... It made me a bit more tolerant......."

All of the families in this study identified sensitivity to sensory issues for their child. Managing sensory challenges are impactful to the child but also impact the activities of the family. The following example is a good representation of how sensory challenges could impact the family. Here is what Xavier had to say about this,"He was hyper vigilant for noise. He couldn't tolerate noise. He couldn't listen to a parade going by within two or three blocks because of the noise. He grew out of it."

In the following excerpt, Rose shares how she felt about finding out that her perfect baby boy was diagnosed with a disorder, which was not what she expected.

> Yeah. I remember when they talked to us in Kindergarten the first time. It was December 18th, a few days before Christmas. I just assumed it was whatever, whatever. They presented to me that my child was other than perfect and which is how I of course saw him. I was devastated. I was absolutely devastated. I thought, how can they do that to people? Merry Christmas and by the way your kid is..I was upset. I was devastated in some ways.

Families generally expect that their child will successfully engage in extra curricular activities, clubs, and sports. Many of the families interviewed expressed disappointment in the fact that their child was neither able to engage in nor enjoy many of these types of activities. In particular, fathers generally look forward to watching their sons engage and excel in sports. Xavier shares some of his feelings about missing out on that joy with his son in this excerpt,"I do feel a little sad. You know I was very athletic and I was very good at all that in high school. In some ways I feel bad that Johnny will never have that experience."

The final excerpt in this section addresses the feelings that Grace talked about with regard to what she expected out of the adoption experience and the outcome of how her experience has actually evolved.

> Even if adoption is different the way it was, those pieces, you felt something different was going on but you didn't have time. And....you don't know when it's coming..... you are sitting at home with your child that you are dreaming of having that is sleeping and doesn't want anything to do with you........At 20 months we noticed that if we deviated from the routine a little bit....that would upset her....she would sit on the floor and spin around. I would have to sit her on my lap and gently put my arms over the front of her. Not restrain her but the comfort of pressure............Quite honestly one of my biggest fears that she would get gang raped and she wouldn't say anything. She wouldn't know it bad or wrong or hurtful or anything......... It's scary.....it's not an option for one of us to quit (our jobs). I will not go down that road for either one of us having a huge resentment against the other. Whether I keep working and he quits, it's natural, you would be trapped in a house, giving up your career, something that you love. The bottom line is Susie is who she is, today and tomorrow, she will need that constant care beyond our being physical position to giving it to her. We will be aging parents one day to a child who is still a 5 or 6 year old.

THEME 4: RELATIONSHIPS ARE CHALLENGING

All of the parents interviewed for this study were able to identify challenges they have faced because of the stress their special child has put on their time, their family, their friends, and their extended support systems. Under the best of circumstances relationships are challenging.

The marriage relationship, the parental relationship, extended family, neighbors, and the community all impact our sense of who we are, how we define our success, and the fulfillment we feel about our lives. Each of us comes with our own unique personalities and differing resiliency factors which impact our ability to manage our relationships.

The NASW (National Association of Social Work) Code of Ethics has six core values. One of its core values is identified as the importance of human relationships. This core value is further defined as an ethical principle. This ethical principal informs Social Workers of the following responsibility: *Social workers recognize the central importance of human relationships.* Social workers understand that relationships between and among people are an important vehicle for change. Social workers engage people as partners in the helping process. Social workers seek to strengthen relationships among people in a purposeful effort to promote, restore, maintain, and enhance the wellbeing of individuals, families, social groups, organizations, and communities (http://www.naswdc.org/pubs/code/code.asp, accessed 03/10/2009).

It logically follows that the functioning of a family system is impacted by the nature of the relationships between the members of the family in that system. The following section contains examples of how these relationships were defined by the families interviewed in this study. It is the goal of this study to add to the knowledge base of Social Workers and other helping professionals to promote successful outcomes in working with families impacted by Asperger's Syndrome. Therefore, the following excerpts are especially relevant to this study.

No matter how hard a parent tries to please their own parents and extended families, sometimes it is just not possible. Almost all of the parents interviewed for this study expressed stories related to the conflict that has arisen between themselves and their extended families. Ed talks about the strain on his relationship with his mother in this excerpt,"So, my Mom never thought we were raising him right, but we could have been raising Albert Schweitzer and she would have thought we weren't raising him right." Steve also reported a similar experience in this excerpt,"The point of conflict is my mom......she is in denial on where Susie is at... My mom has read every article she could on Asperger's..... But she still doesn't understand that there are other overlying factors....." Grace offered the following,"His (Steve's) mother has just flatly said that it's all me and that I am making it up. Attention wise, that this is all my doing. This is not Susie, it is just me, and that I have psychological issues." Rose shared another example of the challenges her family has faced in this excerpt,"I have one sister up in Duluth....She got very judgmental of us at one point in time. We should be reading the bible together instead of Harry potter. Some stuff like that."

The marriage relationship is also affected by the stress of living in a family affected by Asperger's Syndrome. Most of the parents interviewed discussed similar challenges to their relationships as Grace and Steve describe in the following excerpts:

> (Grace) It got to the point with us, for marriage wise, it was we are done. I can't do this. I can't take the mental of that I am being the controlling one. I am doing this for Susie. I don't want to do it, but that is what works for Susie, and that's what I have to adapt to in order to give Susie the structure so we can see how independent she is able to get to.

> (Steve) So we have a lot of stuff that we are going to conflict over, discuss and I've had to learn a lot over the last for years. How we discuss things and I've come a long way in that aspect. We are going to continue to have these little ebb and flows on how we are going to deal with this.

In every family, the dynamics within the home are impacted by all of the relationships. Not only were challenges to the marital relationship identified by these families, but also challenges between and among the siblings. This example provides information on how siblings can be affected by their special needs sibling as shared by Erin."Angela had to have a lock on her door in order to keep Bobby out of her stuff...Daniel had Bobby under foot all the time....Bobby would be interfering with ..... friends....sleep overs....stuff like that. It was really hard on him." In this excerpt Sara is talking about the relationship between her two sons, the older having Asperger's Syndrome, and the struggles she had in getting used to living in a new community. "...... They were fighting and punching each other. I had to be physically in between them.....I couldn't leave them alone..... I was home here in this new place....I was all by myself. I remember just being so frustrated..." Here is another example of the challenged relationship between siblings and some of the outcomes of those challenges as described by Grace in this excerpt:

> Sally is stressed out in her grades, when you talk about the impact of the family. We really feel for Sally. She developed Reactive Attention Deficit as well as situational stress with Susie. When it's quiet you get freaked out where Susie is. Susie has to be with us physically. She is to the point, where she can play in the cul de sac.....Sally really lost about a year and half of school just from the stress from Susie shifting and trying to redirect.

Relationship challenges were reported to extend beyond the immediate and extended families into the community. Grace spoke about her family's experiences related to this in the following excerpt:

> So through all of that, it was very hard, and difficult and painful. We are both very social people and Sally is very social to see Susie getting cut out more and more of circles, and sadly our family getting cut out and reduced and getting eliminated, with neighbors that you thought were good friends......Now we do very little to nothing with people in our neighborhood, if you told us that 10 years ago we would have just completely laughed in your face. Even 5 years ago.

The parents interviewed in this study expressed feelings of guilt, frustration, and sadness over the challenges they experience in relationships through multiple perspectives. In this excerpt Steve addresses his feelings of guilt about his challenges in meeting his daughter's needs. "....... when the girls were doing something wrong.....or Susie, I couldn't figure out, and the guilt I felt afterwards. I would get into her face, and she would just sit there and look at me and start crying." Ann added, "I want it more understood by the public. By the people who have been blessed with children that are normal......Don't judge me by what my child lacks. You thank god everyday that your child doesn't have special needs. Don't judge my child, just be thankful." In the following excerpt, Sara talks about the frustrations she and her husband have encountered with each other over parenting and extended family support:

> .....When I thought he shouldn't or I would second guess myself, I thought I couldn't give in because Robert would think I was giving in when I shouldn't have. We got to the point that we didn't even have time away from them to discuss, and if we did start to discuss and we started to disagree it was like I don't want to discuss this in front of the kids. Oh, how convenient. There is no other time...... I had to have a discussion at 2:30AM......I've gone to a counselor and I wanted to improve things......Robert and I try to get out, but we are lucky if its once a month ..... And my parents would be able to handle them, but my mom took awhile to

> even come to the conclusion that something was wrong. She thought it was parenting. That was frustrating. She thinks she can, if she's firm enough with him, he will listen. And that isn't how it goes.

Erin took a different spin on her example,"They would ask us if Bobby was on medicine, and we would say no, but he has everyone else on medication. There is Bobby time and then there is real time."

David expressed a significant amount of internalized self reflection with his comments on the relationship challenges between him and his family in this excerpt:

> I have to keep checking it and checking it. It is stressful and I want to help and sometimes I think I am part of the problem, and I have to check that....It's a stressful scenario. We can do it some days and sometimes we don't do as good. I value my contact with the AA world and you would be surprised how many people are out there going through this with different names and scenarios....there are times where there is a lot of things that I read into I get defensive. I worry about a lot about her (wife) what's going through her mind. Am I teeing her off, because it is a very stressful scenario? You got to keep reassuring myself. I think that's a product of stress.

Like David, Xavier had many insightful comments about the challenges associated with relationships as a result of his son's Asperger's Syndrome. Here is some of what he shared:

> .....he is intelligent....He has a very dry sense of humor. Most adults couldn't talk to him..... He kind of thinks that most kids are kind of stupid. I don't think he is all that hesitant with telling them so, which might be a reason he is not getting along with the 8th graders......Adults who talk to him are amazed the level of humor, even the teacher says they crack a joke and he gets it, but not anyone else.

In addition to the feelings of guilt, frustration, and sadness shared, many of the parents interviewed in this study, also related experiences of being duped by their AS child. In this excerpt, Steve shares the frustrations that he has experienced in feeling as if he had been taken advantage of by his daughter."She learned how to work us. I guess I didn't understand that, but it has been explained to me since then, talking to various people. She knew that she could get."

Relationship challenges were one of the key issues discussed by each of the participants in this study. As the reader will have noted, the full gamut of relationship issues were identified in the above cited excerpts. Particular issues that were identified by most of the families interviewed included conflict created by the extended family's lack of understanding regarding the AS child's behaviors, the strain on the marriage, and the impairment that has occurred to the sibling relationships.

I felt that one particular relationship aspect was so significant for these families that a segment of the entire realm of relationship issues raised to a category of its own, the issue of peer relationships. Peer groups play a huge role for us all; for these children, the nature of peer relationships and the effects of those relationships were identified by each family as a subject and stressor that spills over to impact the family system. The next theme will address this subject.

THEME 5: PROBLEMS WITH PEERS

When contemplating human behavior, is appears that there are very few people that would prefer to spend their lives in a solitary state. Peer relationships, especially for children, offer the child a dimension and insight beyond the world of parents and families. Carrington, Templeton, and Papinczak (2003) stated that social dysfunction might be the single most handicapping feature of Asperger's Syndrome. Little (2002) went on to say that due to their unusual mannerisms, view of the world, and social deficits, individuals with Asperger's Syndrome are often described as "perfect victims" by their peers because of their profound lack of social skills. Without exception, each of the families interviewed identified issues with peers that have caused stress and anxiety to the child and family.

In this excerpt, Ann talks about her son's lack of social skills in building solid peer relationships in this excerpt:

> .....he doesn't know how to play, the interaction back and forth were his idea was play, you set up the thing and then you move the thing around and if anyone else even touched it....or had a different idea of where something should go, that was pretty much the end of the play.

Like Ann, Ed identified challenges with peer relationships, his assessment was significantly more colorful in the way it was expressed:

> The bullies and schmucks among his peers, will do stuff and not get caught. They will push him and push him and push him and he reaches the point where he has been pushed far enough, and he doesn't consider that he will get caught, and he thinks now is the time.

Sara shared information during the interview process that indicated that issues with peers have just begun. Due to the fact that her son is still rather young, under the age of ten, she is expecting peers issues to escalate in the future as addressed in this excerpt. 'Sometimes he will say stuff, but a lot of times he won't talk to us about it (bullying). I think the teacher knows, and some kids know...... I think it hasn't quite started, but I anticipate it will."

In addition to the insights that Ann and Ed relayed, Grace also talked about the social skill deficits in her son and how those deficits seem to play a role in the challenges of peer relationships. Grace focused on attitude, rigidity, and inflexibility in her comments. common traits of the individual with Asperger's Syndrome as addressed in chapter two's review of literature."... if it doesn't go my way....I don't need you...I would rather be without... There is no tolerance for anything....breaks the rules; he is the first one to tell..... Because he has zero tolerance he can't brush things off."Unfortunately, children can be cruel to each other.

Children with AS tend to be quite vulnerable to the cruelty of their peers. Most of the families interviewed had stories about cruelty their child has faced at the hands of their peers. David addresses one such example in the following excerpt,"He is vulnerable with kids his age and things that kids his age are much more advanced, a little smarter etc....They can therefore handle him, they can make him a guinea pig; they can do all kinds of things."Being called names, enduring harassment, and being ostracized were sadly common themes addressed by most of the parents in this study and depicted with similar statements like this one made by Steve:

> Part of the deal is peer pressure. Sally was telling me....there is another boy down the street that I found out call Susie a retard, ...No one comes up to Susie and tells her face to face probably because she is a big kid....Sally says she hears all the time with little snickers behind the back.

All of the parents involved in this study were well aware of the challenges that their children faced with their peers. The stories revealed a constant challenge for the families in determining how deeply to get involved or in what ways to allow their child to attempt to navigate through these issues as a part of their childhood development. Whether these families were highly involved or remained on the periphery, the concern and stress associated with these known issues was reported to weigh heavily on their minds. In the following excerpt, Rose addresses additional areas of social deficit for her son related to the subject of peers.

> He does well with adults, and he does well with little people, but when he would get around kids his own age, and this was around preschool, he would just clam up. Even now he will come home from school; he will say"I don't know why everyone hates me."... Unfortunately we don't have a lot of kids in the neighborhood. But maybe that's ok.

Not only are one-on-one peer relationships reported to be a challenge for these families to manage and support with their AS children, but so were group settings with peers. In the following excerpt, although Steve illustrates the significant issue of stealing behavior, the example also illustrates the common issue that children with Asperger's Syndrome seem to have when it comes to working in groups:

> Stealing ...kids were missing things out of their desk.....There was destruction of personal property. By the end of second grade, we were having a hard time, because they would do a lot of group activities for social interaction. She couldn't work with anybody, because she alienated herself from other kids, not just in her classroom, but in the other classes. Her acting out that much was sad, so we tried to deal with third grade as much as we could.

To wrap up this section, I want to share two final comments. The first is from Grace, who expressed a comment shared by almost all of the families, "Susie doesn't have friends of her own." The second is shared by Steve, a sentiment shared by most of the parents interviewed for this study, "We can't have a birthday party for her, because there is no one to come. It really tears me apart."

THEME 6: THE SCHOOL EXPERIENCE

According to Fombonne (2003), children with autism benefit most when home and classroom environments are structured to capitalize on their individual strengths and compensate for their deficits, when the classroom offers a high teacher to pupil ratio with individual educational plans, and when parents acted as co therapists to promote the child's generalization of learning.

Students with Asperger's Syndrome have historically not received equitable education accommodations in terms of support, services, and resources as compared to students with classic autism. Asperger's Syndrome students have been called orphans in the educational system (Barnhill, 2007). The following excerpts are just a small sample of the descriptions reported by the parents in this study.

Bullying issues and the school experience seemed to go hand and hand through the reports made by the parents interviewed for this study. Ann describes the issue in the following excerpt: "It's bullying, like everyday it's like this is the day that he comes home and says this kid did this to me, this kid did this to me........ I am in touch with school... getting both sides of it."

The families included in this study reported that they realized early on in their AS child's educational life that they walked a fine line with the school systems between being considered a concerned parent and an over-bearing thorn in the school's side. Ed talks about this in the following excerpt. "We're not the helicopter parents. We're not the ones who say why did you flunk our child on that? We are the ones on the phone, if we need to show up."

The information received about the school experience from the families was either extremely favorable or definitively negative. It appeared that the success or failure of the school experience was impacted largely by the child's educational support team. Sara had very positive comments to make with regard to her experiences in the following excerpt:

> School is great.....Never had a problem. He got good social assistance, and she was on top of stuff. It's been really, really good. He's been in kindergarten, first grade, mainstreamed, and awesome.....The IEP is hard to understand, and every time we go, we rely on other people. Other people are supposed to be there, but they aren't. Sometimes the speech person will show up for a couple of minutes.

Like Sara, Grace also had positive comments to make about her school experience as evidenced by the following excerpt.

> They were amazing. It helped that we knew a lot of them. I'm very well known for being an advocate. I just walked in; we got to choose who our kindergarten teacher for him. Our biggest concern was, we got to look at all the different classrooms, we didn't realize that a lady we knew was a teacher there, and we walked in to a couple of different classrooms. Brady was like I want to be in this classroom, this has a pirate ship, and this has this. This is going to be a disaster, how is he going to focus? We walked into her room, everything was organized, and everything was put away in tubs so there weren't any distractions. She turned around and I had this tear and said Thank you God.

Even when the school experience had been positive, most of the families interviewed for this study reported that they learned quickly the important role they had in being an advocate for their child in the school setting. This comment made by Grace, "I walked in with an attitude to prepare yourself, to have to fight."

Not all of the parents had experienced positive situations with their child's school experiences. In this excerpt, David is discussing the challenges that the school has had with his son and the significant amount of time that his wife must spend on collaborating with the school to meet their child's needs. "Even school has problems. She has to run to the school and take care of it. Sometimes two or three times a day." Erin also spoke about some of her frustrations with the school experience in feeling that her child was not getting his individual needs met in this excerpt, "They said....if he does the homework, they will pass him......They would prefer that he didn't fall asleep in class like he did in the last test. I'm a little bit bitter about it."

Planning for accommodations for the children's individual sensory needs and specialized planning to help the children with transitions were areas that were reported to bring great stress to the families in this study. Sensory issues for children with Asperger's Syndrome are an issue that each of the parents in this study identified in many of their descriptions. David described it this way:

> One of the things....was the sensory things, take sound for example. He couldn't go to church because the music would drive him to a point where he would hide. That carried on to large crowds in school. Always a really big problem to put him in a big class, or have lunch in the lunch room and all the kids chattering and the decibel is way up here.

All of the families interviewed identified the challenge of transition for their child. Xavier made the following comment, "He just does what he has to do and wants to get the heck out of there. Johnny had a real difficult fifth grade. I think it was the transition from fourth grade.............I think that transition is very hard." It seems to be very important that a well thought out transition plan is created for the student to support transition success. In this excerpt Erin discusses this issue.

> They did it gradually so that by his 3rd trimester he was able to take a mainstream class or two and he did really well, consider his handicaps and all. So this year they are going to start him out in 2 mainstream classes. He didn't transition well. He's still fighting them on it.

This theme illustrates the dynamics of the home and school interplay. Grace summarized what all of the families identified as significant with regard to how school impacts their family. "If something is going wrong at school, they think something is going wrong at home. I would say three days, three weeks, three months, even a year later, it is so true... I was concerned child protection was going to come next." Patty very eloquently addresses another common observations made by the parents interviewed in this study. This example supports the significance of the impact that school has on the child's ability to manage life in the family setting: "Teachers love him. Everybody loves him at school......he would hold everything in, and try to be so normal, that he would come home and it would just everything got let loose. I would be on the receiving end of it." Probably the single most significant implication for this study regarding the school and home experience and the impact on the family is addressed in this brief statement made by Rose, "(Researcher): Would you ever see your child have a struggle during the school day and then come home and decompress, causing trouble at home? (Rose) Oh Yes!!"

THEME 7: IT IS WHAT IT IS: LIVING WITH ATYPICAL BEHAVIORS

This final theme section reveals many personal and heartfelt stories that were shared by the families interviewed for this research project. Upon completion of this section, the reader will have gained a deeper understanding of the challenges experienced by the families participating in this study.

In this first excerpt, Ann addresses her resolution of her situation:"...it is the way he is... He will do something a little odd and my brother will say that must be the Asperger's you told me about......he is just part of the family.....You deal with his little eccentricities." Ed has his own way of expressing his perceptions in the following excerpt:

> It's the societal stamping out of narrow diversity. Our kid thinks a little different so there must be something wrong with him. There is nothing wrong with my kid. He doesn't think like the kid next to him. This is good. We've got psychological mono culture. That is a bad thing for our culture, for society, for our species. If you look, everyday you see something that looks like the famous historic figure that changed the world lived and they had Asperger's. Why are you trying to change it man? This is where our geniuses come from. This is where progress comes from. This where the people we need, this is how they think, so why is it wrong? Why does it have to be stamped out and managed and corralled and straight jacketed? I feel sometimes like, because my kid is not normal, not normal doesn't mean there is something wrong with him. There is nothing wrong with him. What's wrong with not be normal. I'm not normal, she's not normal. Why is it that people expect our kid to be normal? Our friends don't expect our kid to be normal, because they know us.

Ed's comments really exemplify a wonderful perspective on the realities of this growing population. His comments are both passionate and thought provoking.

It was evident after talking to the families in this study that they all realized that living with atypical behaviors was a permanent part of their lives. They seemed to have resigned themselves to either accepting their child for who they were or fight the child which would just add to the stresses of living. In this excerpt Sara addresses some of those unique issues related to food.

> He was almost better when he was a baby. He'd eat broccoli and cauliflower but now he doesn't like it. He has problems with texture stuff.... stuff you would think he would eat, like apple sauce, he wouldn't eat.....it was the texture.....He likes carrots. He doesn't like any other vegetable. He will only eat them raw. He used to eat bananas but now he doesn't......He is really picky, he won't eat potatoes, he won't eat homemade French fries, but he will eat the ones from McDonalds. He won't eat pasta, and he won't eat rice, and he won't eat, but he will eat bread and he likes English muffins.

Like Sara, Rose and Xavier also shared their experiences and humor in dealing with their son's issues of food rigidity in this excerpt:

> (Rose) With some of his food, if something was done a little differently, like if it was Minute Rice its Uncle Ben's. Every time we had rice then he would ask if it's Uncle Ben's. It kind of got to be a standing joke. (Xavier) Even the yellow mustard. It had to be French's; it couldn't be Plochman's. I said I'm going to put someone else's mustard in that damn jar. Well, it better be French's.

Accepting and living with the unusual behaviors associated with special interest areas/obsessions were also a common theme discussed by the families interviewed in this study. Grace discusses this in the following excerpt.

> It started out with tools. He was obsessed with tools. He wanted to have his birthday party at Home Depot. We would go, that was his reward, if he did something really well, and we would go to Home Depot. He would look for hours. I came home one day, and he'd had a really bad day. He started to the garage, he was really mad. He took out all the tools and he took them all out, and they were lined up. First it was the hammers, they were lined up the same way and they were touching. Then it was the screw drivers, the Phillips and the regular, and they couldn't touch each other. He would take them home or take them to bed with him and take some wrenches to bed with him. He would lay them next to him and he would say his prayers at night and the last thing he would say was God bless my tools.

Xavier also shares his story of his son's special interest areas/obsessions and how his family manages this eccentricity with the use of humor.

> He will still watch Thomas the Tank Engine if he thinks no one else knows he's doing it. He still refuses to let us get rid of those. We kid him with "When you turn 18, we are going to tape you to a chair and make you listen to Thomas the Tank Engine movies for 18 hours at a time.

Most of the families identified that they experience challenges in carrying out activities as a family. They stated that they need to carefully plan for outings. Rose addresses the challenge of introducing new experiences to her son in this excerpt.

> When he was little, whenever you would do something new with him, he was always kind of suspicious and cautious and he would hold back. I knew with him and when you are a Mom you get a sense of what works with your child. Gentle re-exposure and a little bit more each time was the way he did learn how to do things differently. I remember when the psychologist diagnosed us, between kindergarten and first grade, in terms of parenting, some techniques that might work. I don't remember what they were, but I thought geez I've been doing these for years.....We have just always accepting him as he is. He is not required to be anything different than what he is. I have never pushed that on him. I just figured that's the way they are.

Learning to manage the feelings of living under what was described as constant stress was summarized by Erin with the following sentence. "You learn to either laugh or to cry." Rose describes some of the ways in which she and her family manage these emotions in the following excerpt, "His tone of voice tends to be kind of snappy...he communicates in monosyllables.....He responds in grunts. Every once in a while we play a game....say something nice to everyone...he laughs...He will say stuff like, 'You are not dead." Sometimes humor is hard to draw on in these situations, as addressed in the following excerpt from David:

> ....like the other day I was giving him hell, I was getting down on him pretty bad for staying up all night and keeping us awake and then sleeping all afternoon. He gets stressed out in school and he comes home from school and he goes to sleep. Unfortunately that becomes his main sleep, 8 hours, and then he wants to be up all night. I talked to him the other day and I told him this is it. At 10:00pm at night, I am pulling the plug on the phone and all of your stuff. NO more phone, no more Xbox, no more TV. That's it. And he will sit around. He has to go upstairs and unplug them. He doesn't understand it. He sees this picture to pull the plug. I can see many, many examples through his whole life that he sees things in pictures...I have to do this battle all day, I don't get anything else done, and that's ok. I have to win this battle....

Managing stress, being creative, using humor, and being flexible were all identified skills that the families interviewed discussed in order to manage their lives living with Asperger's Syndrome. The following example highlights some of the adjustments the families in this study reported. Patty reported that she and her family adjusted and managed by"...learning to incorporate that we learned quickly not to let him get tired, hungry or bored. Those three things are dangerous....We did different things....no matter where we were, what we were doing, we carried the little brush for the sensory stuff...."

To identify each and every valuable insight that the families shared would create a lengthy volume of literature too long for the parameters of this project. However, thorough reporting of the data is vital to the understanding of the multi-faceted impact that living with Asperger's Syndrome has on all aspects of a family's functioning. Therefore, the next several excerpts are a smattering of examples related to the topics and insights discussed by Grace in connection with how she sees the impact of Asperger's Syndrome on her family:

Career Issues

With a marriage counselor, individual counselor, and a family counselor...I am putting so much time and energy into her and I am getting sucked pretty much dry. I love my career, but still know where the limits are. I did give up 7 years, I didn't give up, but I was with my family. I got it back on track.... for the sake of my sanity.... It feels like I am putting water in a bucket with a bigger hole, and I wasn't catching up......I got to that point where I couldn't keep giving to the family and not taking care of myself.

Accepting the Diagnosis

That is probably one of the biggest things of relief that I had from Susie getting her diagnosis.......number 1 is not me, and number 2 is not Robert, it's not Susie, It's not Sally, it is what it is. She inherited it......

Supervision and Other Worries

Susie will most likely not get her ears pierced, because of the tactile stuff. It is not worth the risk because of what she would do with the earrings. We have no matches in our house because she was getting up in the night, lighting things. She was also getting up in the night, gorging herself and throwing up. We thought it was some kind of flu...We finally figured it out when a whole bunch of my yogurt was gone. She was throwing up yogurt. She would take herself to the bathroom. That's another concern we had going on. She is lighting fires, lighting candles, lighting matches, getting into food, gorging herself, making herself throw up. Great. Now we are going to have pyromania and an eating disorder.

Being Concrete

The abstract when you are ready. Robert has learned you can't say when you are ready to come down........she didn't get the step of the concreteness. It is not me being controlling it is me adapting to get her through whatever it is. That's her comfort level and that keeps her stress reduced.

Reliance on the Sibling

You just kind of shoot from the hip sometimes. Luckily we have Sally, the 3rd parent......It is the fine line for her. If you go too fast you are totally back to zero. It is a constant chutes and ladders game.

The Rest of the Family

> Susie has got to stop driving our family life. It is a part of it, but letting her at the front and all her needs, and us constantly, it builds up hurt feelings, it takes away options that do they really have to be made that way. It benefits Susie, but we are not any less important or less valued as individuals, or as a couple or as a whole family because of Susie's issues.......Where do we get to weigh in?

Some of Grace's Final Thoughts

> Well, you know, it's a road. One step at a time..... I don't know for you, but it was like ok, so we are speaking English and Susie is speaking Japanese. Now we need to learn how to speak Japanese. The letters aren't even the same, which it's taking us a long time just to learn her language.....Now that we know, is that we have to figure it out.

Learning to live with Asperger's Syndrome impacts all facets of family life as the previous excerpts demonstrate. In chapter five, I will interpret the data collected and consider the practice and policy implications of this study, including recommendations for further research.

Chapter V

DISCUSSION AND IMPLICATIONS

This chapter discusses the implications of the data presented in Chapter IV of this study, which provided insight into the lives of six families who have a child with Asperger's Syndrome/Autism. From the interviews seven themes emerged. The themes are discussed in relation to the impact on the family of living with Asperger's Syndrome. In addition, these themes are explored based upon what was previously discovered in the review of literature. Next, implications of the study are discussed. Finally, limitations of the study are identified along with suggestions for future research within the professional field of social work as it relates to working with family systems. The chapter ends with a conclusion and summary section.

THEME 1: WHY IS JUNIOR SO ODD?

With regard to this theme, the parents identified signs that their child was developing differently from his/her neurotypically developing peers. Improved early intervention and diagnostic strategies are needed so that years of questioning and months of looking for the correct diagnosis, and in some cases, the accurate diagnosis, can be hastened. Parent's instinctual suspicions should not be pushed-aside only to later be validated. This all too often can lead to missed opportunities for valuable early intervention.

Although a diagnosis of any kind placed on a child can seem tragic and overwhelming, in all cases, the parents in this study were ready without hesitation to accept the diagnosis and tackle the steps needed to best meet their child's need. This leads to implications for the health care system, and specifically for those physicians treating very young children. Primary health care providers must be in tune to the concerns voiced by parents. Being the first line in the referral process for children suspected of being on the autism spectrum, primary care providers can refer children suspected to have autism to early intervention services and/or further testing.

With the diagnosis, parents begin an overwhelming journey of learning about the disability, understanding their child's needs and behaviors, and planning for their family's future. Early and accurate diagnosis also has important implications for other helping professionals, including social workers. Case planning for the family, which includes referrals and access to appropriate support services such as respite care and early educational programming, is dictated by diagnostic criteria which is the foundation of eligibility requirements for most support services and for approved insurance coverage. Effective support services for the family will enhance the family system when there is an early diagnosis.

THEME 2: WHAT KIND OF HELP SHOULD I ACCESS AND WHERE DO I FIND IT?

As the family moved into the preschool years and watched the gap widen between their child and other children the focus became how to best meet the needs of their growing child. After receiving the diagnosis, most of the families were given information on early intervention services, but it appears that the younger the child when diagnosed, the more information regarding services was offered. The older the child, the more limited the referrals to services seemed to be. Speech therapy was the service most frequently reported to have been received by families. None of the families reported being offered any type of counseling services to help in their family adjustment to their disabled child's needs. The implication here is that in addition to identifying the needs of the disabled child, there needs to be increased attention to supporting the family. Support should take the form of assisting families with education about the disability and coping skills to help them enhance their abilities in successfully supporting their AS child.

As each of the children became older, instead of services being increased, in all cases, services were decreased. In many cases services were discontinued. Finding that services end for these children is concerning since the literature indicates that positive outcomes for children with Asperger's Syndrome (AS) declines as the child ages. As Wolff (2004) reported, the behavioral adjustment of children with autism can be much improved with early intervention but the long term outcome prognoses are still questionable. Jennes-Coussens et al. (2006) also reported that the effects of AS are greatest in adolescence and young adulthood and can add additional strain on the care giving primary family. Parents reported that as their child grew older their parental knowledge of the types of support services available became increasing limited. Furthermore, an inability of families to find well trained support services, ongoing discord with educational systems, and adequate respite care further implies that adequate services continue to be needed for these families on an ongoing basis.

Although most of the families were familiar with support group opportunities, few of the families had taken advantage of this option. The families who did pursue this option found that the support groups they attended failed to meet their specific needs. It was also noted that most of the groups that they attended were geared towards either younger children or lower functioning children. The needs of the families interviewed for this study were significantly different than those of the families attending the support groups that were accessed. Time, location, and convenience were also factors in the lack of utilization of support groups cited by the parents interviewed for this study. Therefore, support group opportunities that focus on meeting the needs of the family specifically living with AS are indicated.

In the current economy of dwindling support service budgets, staff downsizing, and many rural areas experiencing a significant lack of trained resources, it is important that increased support services be created and adequate training be provided to support these struggling families. Networking, increased budget allocations, and creative support services are clearly needed to meet the needs of the growing population. Based upon the data, examples could include large group models for support groups, group educational opportunities for families living with AS, and specialized services providers working in regionalized areas.

THEME 3: THIS IS NOT WHAT I EXPECTED

The most important person in the child's life is his/her parents, and being the parent of a child with AS places many extra demands on the parenting role. Frequent appointments, changes in career plans, loss of income, needing to learn the child's language and needs specific to the child's disability, all while finding ways to continue to meet the needs of the neurotypically developing children in the family, were all reported to cause a great deal of stress to these families. In addition to managing the emotional and physical stressors of having a disabled child and finding both formal and informal support systems to help maintain the family system continue to be a challenge. The data clearly indicate that extensive and ongoing parenting support is needed for these families. Simple things like play groups for AS children and specially designed day care programs should be created to help give these caregivers a break so that they can meet their own emotional needs as well as the needs of the other members of the family. Another example of helping ease the challenges and stresses placed on the family is coordinated medical appointments to reduce the amount of time families spend running their AS child around and freeing up their time to spend time with other members of the family.

All of the parents talked about the strain their AS child placed upon their marriage. The changes these families have needed to make to their home lives, social lives, and extended family lives are far reaching. Simplifying life, avoiding chaotic situations, and slowing down are examples of the accommodations that these families made in order to meet the needs of their disabled child. With divorce rates on the rise, and even higher rates for families of disabled children (about 80% according to http://asa.confex.com/asa/2006/techprograms/S1940.HTM, accessed 01/19/2009), support services such as respite care, alternative care providers, appropriate school programming, and education for families must be developed and enhanced to help marriages stay together while families try to meet the demands of their disabled child.

Time, attention, and finances were all reported to be strained due to caring for a child with AS. Most of the families agreed that child rearing in their situation was a 24 hour job. Despite these challenges, all of the families were able to identify how having a special needs child has enlightened their understanding of others. Most of the families commented that they have gained insight into recognizing the unique attributes associated with dealing with all people and have gained a more tolerant stance of others because of their experiences in living in a special needs family. These insights need to be explored for these families to help them see the strengths they bring to their families.

Feelings of despair and frustration accompanied with concern for the future also embodied the insights shared by these families on the changes they have been required to make to their life scripts. Most of the parents are concerned about what the future holds for their disabled child. These concerns include questions about who will be there to watch over and support the AS child when they are no longer able to provide that care. In all cases where siblings were involved, the families depend upon the neurotypical child to look out for the future needs of the disabled child while feeling conflicted about placing their other child in that situation.

THEME 4: RELATIONSHIPS ARE CHALLENGING

The experience of parenting a child with AS is stressful and the impact on the entire family system is tremendous. All of the parents interviewed for this study had utilized some sort of marriage counseling, either professional or spiritual. In no cases were any of the families offered support services in the form of family therapy to help them deal with the stresses of managing an AS affected family, yet all of the families indicated an interest in receiving this type of support service. These types of services need to be more readily available, expanded, and/or provided to these families.

The fact that holiday events, neighborhood activities and community outings required careful timing, planning, and back up plans were common points of discussion for all of the families. Relatives and friends can offer a tremendous amount of support to the family living with AS. Unfortunately, lack of understanding among friends and family members were also significant points of discussion for those interviewed. One of the unique challenges associated with individuals afflicted with AS is that they are not easily recognizable as a person with a disability. Yet, their actions, behaviors, and words blatantly call attention to their disability. This often causes the unaware person to be confused and often intolerant of the oddities of the "normal" looking individual's behaviors and statements. In all cases, the parents gave examples of being judged by others, excluded from events, and alienated from once enjoyable family functions and community events because of their child's atypical actions. Family and community education is indicated to help decrease these issues.

In this study, about half of the extended family members were supportive while the other half were neither accepting nor understanding of the special needs of the family. Several of the parents stated that educating their family members was the most successful way they have been able to have their family members come to understand the unique challenges of AS and the needs of their family. Understanding the disability and accepting the child were not always correlated for some family members. Close proximity and positive family relationships seemed to be the most significant indicators of the level of support given by extended family members. Few family members took an active role in supporting and/or providing direct child care to the affected family. In most cases, the maternal grandmother was the most supportive extended family member.

There are many implications of the findings for family involvement. Most importantly it is critical to educate extended family members about the disability and empower them with knowledge and empathy so that they will be able to emotionally support the family and child. Through education, extended family may be more willing to offer support to the family in the form of respite care. Utilizing willing extended family members for respite care would provide a much needed break to the family and children living with the disability. Simply empowering extended family members to better understand the disability and become less judgmental of the parenting and challenges being encountered within the family would foster a supportive environment for the family living with AS.

Some of the parents shared that their experience has been positive in the sense that they love their child and are deeply committed to providing all that they can to give their child as normal and happy a life as possible. As stated above, most of the parents talked about the necessity of adapting the family schedule, having routine to their day, and providing structure and consistency to daily life. Pre-teaching and the use of social stories were also strategies employed into daily use by most of the families and are implicated for continued use.

It was reported that children living with a brother or sister with AS have been affected in many ways by living with a sibling with the disability. Of the six families interviewed, five of the families had more than one child. Three of the children had younger siblings and two of the children had older siblings. Parents reported a mix of sibling outcomes. Those with older siblings reported that the sibling was either a great support for the AS child or had separated him/herself from the affected child.

The AS children who had younger siblings all had similar situations. The younger siblings all had strained relationships with their disabled sibling. Most parents reported that younger siblings were aggressive towards their sibling, argumentative, and one parent reported that their child was diagnosed with a stress-related disorder due to the impact of living with an older sibling diagnosed with AS. None of the parents reported having successfully accessed support services for their neurotypically developing children. One family did send their younger child and their child diagnosed with Asperger's Syndrome to joint therapy sessions. This family felt that they were helping to support their neorotypical child by providing this opportunity while also helping their diagnosed child concurrently.

Most parents responded to the challenges of the sibling relationship by including the neurotypical child in conversations about their disabled sibling's needs and challenges. These findings indicate that further study of sibling's emotional needs and possible interventions and support services are warranted. Sibling support groups and skill shops are starting to be a service offered to affected families. Limited options for these youth do exist. The few programs available or not yet available in rural settings, are expensive and held during inopportune times of the week.

THEME 5: PROBLEMS WITH PEERS

All of the parents in this study identified peer issues and bullying as a significant problem for their child. The data I collected in this study supports the literature that describes children with AS as inflexible, single-minded and self-centered. These characteristics make it difficult for children with AS to engage in reciprocal play or develop friendships. Most of the parents described their child's inability to compromise in peer friendships as stressful not only for the child, but also for parents and the family. Social skills training approaches need to be a focus of intervention for these children and these families.

Although bullying was identified as an issue that impacted all of the children in this study, the younger the child was, the less likely that bullying was identified as a significant issue. This is most likely due to the fact that younger children are often less aware of the differences in others. It seems that as children age and their social understanding of the world develops, they begin to express their understanding and tolerance of others with whom they interact. Therefore it is important to educate neurtypically developing children on disabilities, tolerance, and the acceptance of others to lessen the change for bullying behavior to develop.

As the age of the child with AS increased, so did the examples of bullying, harassment, and voids in peer relationships. For all of the parents, worrying about their child's future included concerns about their child being alone and solitary in their future lives due to their inabilities to build and maintain lasting peer relationships. Most of the parents indicated that their child indicated a desire to have friends, but had an inability to know how to manage those relationships. Additionally, the vulnerability that these children experience with their peers was cited as heartbreaking to most of the parents involved in this study. Again, this indicates a need to support these families to help them articulate their concerns, support their child in learning skills to be more socially independent, and provide avenues for peer social skill training.

Most of the parents stated that their child was able to get along well with adults and get along well with children younger than themselves, but were unable to get along with their peers. The families interviewed in this study indicated that this issue caused a considerable amount of stress on the family. The families interviewed indicated that because of their disabled child's problems with peers, they believe that they have become their special needs child's primary source of support and guidance and believe that they will need to remain in that role throughout the disabled child's life span. One of the parents summed it up in five heartfelt words: *"It really tears me apart."* It is clear that supporting these families to enable them to continue to support their AS child is critical. Supports must include individual, community, state, and national support through service providers and funding streams.

THEME 6: THE SCHOOL EXPERIENCE

As was identified in the beginning of chapter four, the themes that evolved during this study are interrelated. One of the most significant overlaps occurred between issues with peers and the challenges of peer relationships within the school experience. As one could expect, bullying was identified has a significant challenge in the school experience for these families. Setting up the school environment for success of the child requires tremendous amounts of time, energy, and coordination between the school and parents. These challenges included navigating the educational systems, participating in multitudes of ongoing meetings, establishing new relationships with different teachers every year, and walking the fine line between being an advocate for the child while not being labeled as a reactionary parent.

Opinions of the school experience were either quite positive or painfully negative. Establishment of the Individual Educational Plan (IEP) for each child was depicted as a hurdle that leads to increased understanding of what was needed for their child in the school setting. Some of the families interviewed for this study felt that the IEP was valuable while others felt it was insufficient in meeting their child's needs. Those families who reported feeling that their child's IEP was insufficient stated that this lack of perceived accommodations in the school setting caused them increased anxiety. This illustrated the impact of the school relationship on the family. Stories revolved around stress, anxiety, and high emotions when discussing how the needs of the AS child had been met or not met by the schools. Most parents indicated that the feeling or perception of being heard by the teachers in planning for the child led to increased satisfaction and decreased anxiety for the entire family system.

All of the parents indicated that the outcome of the school day had a huge impact on the child's ability to be a regulated member of the family in the evening. Good days at school translated into a child coming home with the ability to move through the remainder of his/her day with relative ease. However, if the school day was negative, the entire family would experience fallout from the child in the evening. Behaviors reported included physical aggression towards family members, increased defiance of family rules, and an overall increase in tension and disequilibrium for the evening hours. These negative behaviors impacted the entire family system for the remainder of the day leading to increased tensions within the home environment and loss of quality and enjoyment of time together as a family. Interestingly, most of the parents reported that school officials would often assume that if the child was having a bad day at school, there must be negative things going on in the home. The families found this assumption to be insensitive and insulting by their report.

The issue of mainstream classes vs. self contained and special education classes were discussed by all of the families. The families reported that they were more impacted by whether they felt that the school listened to their concerns than by whether their special child was placed in mainstream or specialized classrooms.

All of the parents talked about the importance of school staff being alert to the transition needs as well as the sensory needs of their children. Transition needs were described as the child moving from school to school as they age and from classroom to classroom through the school day. Examples of sensory issues that was of significant concern to parents included noise volume, class sizes, homework amounts, unstructured time in school like lunch and passing periods, and inflexible teachers.

Most of the parents expressed frustration with regard to the fact that even if a child has a professional diagnosis of a disability outside of school, the school can discount that diagnosis if they do not feel that the child's ability to learn in the school environment has been impacted. All of the parents that talked about this, felt frustrated that schools had the ability to discount outside diagnoses and withhold special educational services to their child. Changes in the policy of allowing schools to rely upon their own internal evaluations and discounting outside professional evaluations may be warranted.

Parents also identified the challenges that were encountered when they came in contact with educators that felt that the child should fit into pre-determined modes of teaching and expectations. All of the parents involved in this study identified the importance of recognizing that each child with AS has individual needs and that programming needs to be designed to meet those individual needs. For parents that have had supportive and successful school experiences, their feelings towards school were positive and supportive. For these parents, their examples included daily communication with educators, experiencing meetings with educators in which their suggestions for interventions and supports were implemented, and experiencing a general feeling of being treated as an equal member of the educational team with input and ideas that were acknowledged, valued, and supported. For those parents whose experiences have been negative, their feelings towards school were expressed in terms of frustration and hopelessness. Most of the parents in this study had come to the conclusion that they were not as concerned about being liked by the school personnel as they were with getting their child's needs met. Clearly there are implications from this study that support the need to ensure that educators have an improved understanding of the needs of children with AS, acquire increased understanding of the disability, and be supported in the educational environment with paraprofessionals, in-services or workshops, and ongoing access to enhancing their understanding of this complex disorder.

In summary, when the child with AS has a positive school experience, the home life tends to also be more positive; and for those children who have a negative experience at school, their frustration is carried home and negatively impacts the functioning of the family system.

THEME 7: IT IS WHAT IT IS: LIVING WITH ATYPICAL BEHAVIORS

One of the most significant adjustments was related to accepting special interest areas, which played a large role in the development of this theme. From Thomas the Tank to special card games to the Titanic; from monkeys to tools; and from reading to computer gaming, the families interviewed in this study have found ways in which to incorporate their child's special interest areas into positive adaptations which have undoubtedly helped their children to thrive and grow. These families chose to embrace these special interest areas instead of fight them. This has led to increased tolerance for not just their special child, but for all individuals.

Families also realized early on in their child's development that accepting their child for who they are instead of whom the parent wanted them to be would lead to a more positive outcome for all family members and lower the stress levels in the home. All of the parents found the use of humor to be a significant source of strength and value in the day to day functioning of their family life. I attended a workshop on depression a few years ago and the single most important item I took away from that workshop is the following statement: "Our children are going to be who they are going to be, not who we want them to be." Helping professionals have a responsibility to help families living with AS internalize, embrace, and understand this concept.

With regard to the family relationships with others, most of the families indicated that they have decided that the people that they choose to surround themselves with must be accepting of who they are as a family. Individuals unable to support their entire family, were not individuals with whom these families have chosen to maintain relationships.

Another significant issue related to this theme was that all of the parents identified food issues with their AS children. From only eating certain types of foods, to over eating and purging, food issues were a common cause of stress for each of the families interviewed.

Additionally, medications, therapeutic interventions and appointments, and parades of specialists entering and leaving the family home were all examples used by the parents to illustrate what living with their special needs child is like. Medical doctors, speech therapists, occupational therapists, physical therapists, psychologists, psychiatrists, and social workers have become common fixtures in the lives and in the homes of these families.

Arranging life around routine, structure, consistency, and keeping the AS child well rested, well fed, and calm also ruled the daily lives of the families interviewed. Most of the parents have also realized the importance of taking care of themselves in order to be able to take care of their AS child.

Many of the accommodations the families have made have become such a normal part of their daily existences that they no longer differentiate between what is typical family life and what has become the typical life for their unique family system. In reality, who is to say what typical means anyway? The accommodations were identified as flexibility, a willingness to adapt, change, and learn as some of the key pieces that each of these families demonstrated as a basis leading to their ability to carry on.

In summary, all of the families questioned themselves on just how much they should accommodate their lives for their AS child and at what point those accommodations should be limited. The families in this study also voiced the concern they had that they did not want to forget that their lives were multi-faceted and they needed to attend to not just their AS child, but each of the other members in the family and the family system as a whole. All agreed that learning the language of Autism and Asperger's Syndrome is an ongoing adventure that knows no end and one in which they encounter challenges along every step of the journey. Further research into these thoughts is needed. Understanding Asperger's Syndrome and the impact of the disability is in its infancy stage.

RELATIONSHIP OF THE RESULTS TO PREVIOUS THEORY/RESEARCH

The theoretical aim of this study was to listen to the life stories of the six representative families living with Asperger's Syndrome and gain a deeper understanding of the impact of the disability on the family system. The data received throughout the course of this study supported the literature. All of the biological families included in this study were able to identify extended family members that presented oddities and eccentricities similar in nature to the diagnosed child. Debate continues to be ongoing as to whether autism and AS is related to environmental factors or increased medical knowledge (Wolff, 2004). The results of this study suggest that there may be a genetic component to autism due to the reports from the families interviewed that have other family members diagnosed with an autistic disorders.

Schnur (2005) stated that the typical age of diagnosis of AS is 11 years of age and parents can generally trace concerns regarding their child's development to as early as 30 months of age. In this study, of the six children identified, one child was diagnosed with AS at the age of 4, three at the age of 5, one at the age of 7, and one at the age of 11¾. It is my hope that although Schnur (2005) was able to identify the fact that parents noticed signs of AS at an early age, the age of diagnosis is decreasing as a result of advancements in understanding of AS since Schnur's 2005 study. The data implies that positive advances have been made in earlier diagnosis for these children and perhaps parental concerns are being weighed more heavily by professionals.

The topic of special interest areas came up and existed for each of the children represented in the study. According to Winter-Messiers (2007), special interest areas significantly impact the entire family system and occur in over 90% of children with AS. Co-morbid diagnoses of depression and ADHD existed in the majority of the AS children identified in the families studied. Ghaziuddin (2002) stated that co-morbidity is often the rule rather than the exception in Asperger's Syndrome.

The topic of the stress of parenting a child with Asperger's Syndrome was addressed by each of the families in this study. Pakenham, Sofronoff, and Samios (2004) addressed the fact that parents of children with AS are challenged greatly by the uneven development of their children and are at increased risk of developing psychological difficulties. According the Gray (2006), autism ranks among one of the most challenging of all developmental disabilities that can exist in a family. Problems with communication, emotional expression and antisocial behaviors combined, place tremendous stress on the family. The excerpts cited in Chapter IV support Gray's (2006) findings. From this, it is implicated that intensive and ongoing support of parents raising children with Asperger's Syndrome is warranted.

A Dellve et al. (1999) study stated that 60% of siblings were at increased risk for maladaptive behaviors due to living with an AS sibling. The data collected in this study supported these finding. Dellve et al. (1999) further stated that there were several positive effects on healthy siblings including maturity, sensitivity, and enhanced compassion, high level of involvement in the affected sibling's life, strong feelings of responsibility, and an emphasis on the positive aspects of the family's life. These findings were also supported by the data collected in this study.

In this study, educational challenges played a central theme in the family stress levels in so much as positive experiences in school led to positive interactions at home while challenges at school carried over into challenges and decompression type behaviors related to struggles in the family home. Fombonne (2003) stated that autistic children benefited most when home and classroom environments were structured to capitalize on their individual strengths and compensated for their deficits and when parents acted as co therapists to promote the child's generalization of learning.

Carrington, Templeton, and Papinczak (2003) stated that social dysfunction might be the single most handicapping feature of Asperger's Syndrome. The outcomes of what was shared by each of the families interviewed for this study including friendships, bullying, and general strain on the family system agreed with Carrington's 2003 findings. Treatment options and outcomes were relatively minimal in the literature as were the treatment experiences of the families in this study. According to Tsai (2007), treatment and support of the AS individual can take many forms and there is little evidence-based information about pharmacological treatments of individuals with AS. Adult outcomes were not addressed as no adults diagnosed with Asperger's Syndrome participated in this study.

IMPLICATIONS FOR PRACTICE

There are many implications for practice improvements. In this section, I will briefly summarize the suggestions that emerged as a result of the data gathered. Suggestions are further discussed in the summary and conclusion section.

For the child, the first three improvement need areas include earlier intervention, integration of and attention to the unique sensory needs associated with the day to day life of the AS child for increased self-regulation skills, and education of primary care givers for accurate diagnosis. Focusing on the positive attributes of the child to build upon those strengths is needed. One method to achieve this would be to use the child's special interest areas for building educational, behavioral, and employment goals. Additionally, the extensive use of planning strategies to include pre-teaching, social stories, and stress reduction techniques to prepare the AS child for life's transitions are also practice implications. Finally, creating opportunities for social skill growth in the form of peer/friendship groups, buddies at school and in the community, and support groups for AS children as early as possible are all examples of practice modalities that can help support the AS child.

For parents and siblings, many practice implications were also identified. First and foremost, primary care professionals need to listen to and take seriously the concerns expressed by parents of these children. Second, immediate and comprehensive support service referrals to agencies that provide case management services, respite care services, and support services such as PCA (Personal Care Assistant) services must be made to support parents. Third, comprehensive case planning for the whole family is needed. The focus should be on the person in environment philosophy or systems theory perspective that identifies the impact of the disability on not just the child, but the entire family system. Career flexibility for parents is also needed to enable families in maintaining their standard of living while financially meeting the needs of their entire family, and specifically meeting the needs of their disabled child.

Further development of easily accessible specialized support groups for parents, siblings, and the AS child are needed. Continued services to the child and the family beyond the first few years of the child's life are also implicated. Access to family therapy along with coordinated appointments would help parents manage their time and stress. Finally, specialized training need to be accessible to families so that they can develop a lifestyle that successfully supports their AS child. These recommendations relate to programming that is easily accessible and immediate. Families need to know what services are available to them and how to easily access them.

For the school environment, extensive and specialized education of all school personnel is needed, bullying awareness programs needs to be enhanced, and the school environment needs to be flexible so that the individual and unique needs of each AS student can be met. This can be done through efficient use of the IEP and through collaborative efforts with specialists in the field. Buddy programs need to be developed to enhance peer relationship building. These programs will also increase student understanding and tolerance of their disabled peers.

I recently attended a specialized training, given by the educational advocacy group P.A.C.E.R. (Parent Advocacy Coalition for Educational Rights), and heard the following quote from one of the participants, "Once you have met one autistic student, you have met one autistic student!" All school personnel need to understand that each autistic individual has unique strengths and needs which need to be built upon through specialized programming. One size does not fit all.

A number of implications were gleaned from this study that are applicable to the extended families of the AS child as well as to the communities in which they live. Education related to AS is of significant importance to extended families, support systems, and the community. Education must focus on the key deficits of the disability, the way individuals with AS process information, how to identify a person with this disability, and a focus on their limited understanding of the social world. Most importantly, non-affected individuals need to learn not to blame the behavior on the AS individual, in much the same way that the general public does not blame the one legged man for his inability to run. This increased understanding will lead to increased patience and tolerance shown to individuals with Asperger's Syndrome.

An increase in specially trained professionals ready to work with the AS population is needed. Increased funding for services for this population is an implication currently being explored at the federal and state levels and needs to maintain its momentum. Funding support needs include increased medical, emotional, and behavioral health service coverage to practitioners by private and public insurance carriers. Funding for providers who are specially trained to provide quality respite care is also needed. The current respite care programs are inadequate to meet the needs of this population.

Other implicated practices include community supported, sensory friendly events to support the AS population and encourage and support social skill building. Increased support and programming from the spiritual community for this population is also needed. Since relationships outside of the immediate family system tend to be limited, it may be possible for these individuals to have some of their emotional and social relationship needs met through religious organizations with proper programming.

IMPLICATIONS FOR FUTURE RESEARCH

I have categorized the implications for future research into four categories: the Individual with Asperger's Syndrome, the Family affected by Asperger's Syndrome, Working with Asperger's Syndrome in the School, and Asperger's Syndrome with Support systems and the Community. Asperger's Syndrome has only begun to be a recognized disorder since the early 1980s. Due to this, limited research exists on everything from understanding the etiology of the disorder to adult outcomes.

Individual with Asperger's Syndrome

- To better serve individuals with Asperger's Syndrome, it would be helpful if future research focused on developing ways by which the disorder can be identified and diagnosed earlier and with greater accuracy.

- Further research would be beneficial in determining what types of early intervention provide the most favorable outcomes and which types of sensory interventions and supports achieve the most favorable results.
- Developing data to support or deny the value of offering specialize education to primary care physicians on the identification of AS would also be helpful.
- Research into identifying on which of the positive attributes on which to focus when working with the AS child, as well as following how special interest areas of the AS population help or hinder their development throughout their lives, could be helpful.
- Finally gaining a more comprehensive understanding of effective transition planning strategies and effective methods to be used in social skill training are two other potential implications for future research.

Family

- To offer increased support to the family, case planning through social services and/or other helping professionals should focus on planning not just for the special needs of the AS individual, but also for the needs of the entire family and the interplay between them both.
- Research into how long services should be provided to the family and child, and which are the best services to provide as compared to outcomes, would be helpful.

- Conducting research on how to streamline the multitude of appointments that the family must coordinate could be helpful.
- Now that we know how significantly impacted the family system is with regard to living with AS, research into the most successful ways in which to educate, prepare, and support the family for the challenging role ahead of them would be extremely beneficial.

School

- Research into the most beneficial modifications needed in the school environment, school curriculum adaptations, and graduation standards are all fodder for future research.
- Because social skill deficits are one of the most significant issues of challenge for the AS student, and children with AS are often described as"perfect victims" (Little, 2001), research into what needs to change with bullying programs, the development of buddy programs, and creating peer acceptance strategies are all points of interest for future research.

Support System/Community

As the body of research into methods by which to educate the extended family, support system, and community on meeting the needs of the AS population grows, so must ideas for future research.

- Determining the value in increasing the number of trained specialists to work with the AS population and what specialties would be most beneficial are also points of further study needed.
- A focus on understanding how our society has developed into what seems like a one size fits all philosophy, especially with regard to societal norms, and how that value system could be adjusted to support the AS population would be an interesting topic of study.
- Research into how funding programs for certain populations are defined, and why certain populations receive more funding support than others is also implicated for future research and policy.
- Understanding the decision making process on how and why insurance carriers identify which disabilities to cover and which to deny is also an interesting topic of study.
- Research into how respite services are created and why certain programs have been developed for certain populations could also add to the body of research on meeting the needs of the AS population.

Do sensory friendly community events help support and develop tolerance, acceptance, and skill building for the AS population? What are spiritual communities currently doing to support their AS community members? Is it beneficial to help the public identify the AS person? Can supporting special interest areas help with future employability and success in financial independence? Are pre-teaching and social stories helpful support modalities? These are also interesting subjects that could be studied in the context of meeting the needs of the individuals living with Asperger's Syndrome and their families in our communities.

LIMITATIONS

This study has several limitations. The sample consisted of 11 parents interviewed from central Minnesota. The age range of the identified children whose parents were interviewed was 7 to 16 years and all of the children and families were Caucasian. Although the data are rich from this limited sample, those who did not participate in the study may have offered additional insight into the topic. Those who may have had information to offer but were not interviewed may have been unable to participate due to time constraints, personality limitations, stress, or skepticism about research projects. Those who responded and participated in this study may have been more comfortable with their situation in terms of their child's diagnosis, level of functioning, services being received, treatment received by professionals, or general place in life at the time of this study.

The sample obtained may have consisted primarily of outspoken, self assured parents and not of those who are currently experiencing overwhelming struggles with their child, or other issues such as ill health, poverty, homelessness, or personal mental and/or emotional health issues. Because both parents in all but one case was interviewed together, it is possible that the information received may have been shared differently had the parents been interviewed separately. Thus, another suggestion for future research is to speak with each parent individually and compare and contrast their perceptions of their experiences in living with Asperger's Syndrome. Since the study was done with volunteer interviewees, all but one of the families was not familiar with the interviewer. It is possible that this lack of familiarity with this interviewer may have limited the sharing of difficult feelings and personal information. In general, this could have limited the scope and range of the information collected. However, over familiarity with the researcher could have likewise hampered objectivity and forthrightness of the discussion.

When considering the limitations of any study, Heppner and Heppner (2004) offer helpful insights. They state that research is, by nature, a public activity. As such, it is subject to criticism and skepticism, as well as praise and adulation. All research is flawed in some ways. The perfect study is nonexistent. All research is a trade-off; building strength in one methodological area may bring weakness to another.

SUMMARY AND CONCLUSION

Living in a healthy family system is a challenge in the best of circumstances and raising children is a daunting experience. Raising a child with Asperger's Syndrome sends a family down a path that they had neither expected nor would have generally chosen. Families who have a child with Asperger's Syndrome/Autism share similar experiences including stress, fear, frustration, anxiety about the future, and isolation. The family must alter their daily living patterns in order to provide structure, routine and consistency to help their AS child cope with day to day life. These families often find themselves in conflict with friends and extended family that do not understand their situation nor understand the unique challenges in which they live. Additionally, families living with AS have unique challenges in navigating the educational system, supporting a child who is invariably the target of buliies, and planning for the future of a child who is unable to navigate the social world in which we live.

Parents generally noticed early on that their child was developing differently than his/her neurotypical peers but had no idea with what they were dealing. When the correct diagnosis is reached, the quagmire of support services, specialists, and professionals can be overwhelming as well as intimidating. During the school years the challenges of peers, school, and relationships create mountains to climb and valleys to scale. The lack of peer relationships that most AS children encounter poses additional stresses on the family system as the family then is left to shoulder the full ongoing physical, emotional, and social needs of the AS individual which generally shift to a child's peer group. The family's world continues to revolve around accommodating their special child often at the expense of their own career goals, interests, and other family member's needs.

Setting up an environment at home, at school, and in the community for their AS child often becomes an exhausting task. Often, just when supports and services for the child and family seem to be offering stability, those supports end due to the child's increased age, a transition to a new school, lack of knowledgeable resources, or decreases in funding sources. The family is left teetering on the edge of exhaustion, speaking English, while raising a child figuratively speaking Japanese. While parents grapple with feelings of sadness over the loss of what could have been, face the challenges of balancing the family system as a whole, and attempt to meet the needs of their special child, the bullying intensifies, peers issues escalate, and the future quickly approaches.

Finding appropriate, accessible, and adequate services becomes the exception, not the norm of the early years. The neurotypical siblings continue to take a back seat in the family system. In some cases, the non-affected sibling is able to be supportive of the family. Often, the neurotypical sibling develops conflicted relationships within the family. In addition, the marital relationship is strained and there seems to be no light at the end of the proverbial tunnel.

This is where the helping community needs to offer support to the family system. The strengths of the family system need to be built upon. Support groups targeted toward not just the parents but the siblings must be further developed in order to support these challenged family systems. Accessibility, convenience, and trained facilitators must be enhanced to meet this need. Special events for families living with Asperger's Syndrome, community education, and sensory friendly activities are just a few of the recommendations gleaned from this study.

With regard to the educational system, the most important change needed points to the problem of bullying. Without a doubt, issues of bullying and the stress it causes the AS child is the major contributor to the stress and anxiety brought into the family home. Education to include business owners, law enforcement representatives, the judicial system, and the community at large, is critical. School districts need to gain the courage to address bullying of all kinds on a larger scale than currently exists. In this study bullying by peers was reported at 100%.

Increased understanding must be created regarding the population of individuals with AS. Because the individual with AS is often not identified by appearance as having a disability, intolerance and ignorance runs rampant for this population. Increased tolerance of the unusual and atypical behaviors displayed by individuals with AS will increase tolerance and acceptance in the community and will lower the anxiety that families experience with their neighbors.

At the national level, increased funding is needed, along with grass roots attention, to the exploding population of individuals affected by AS and their families who care for them. Financial support to expand diagnostic accuracy, early intervention strategies and services, and pharmacological advancements are all areas that can potentially improve the lives of individuals living with AS and thus improve the lives of their families who provide their care. As with any worthy cause, advocacy by families, for families, and with families of leaders is warranted to further the advances being made on the local, state, national, and international levels in understanding individuals with Asperger's Syndrome and the impact the disability has on those who love them, their families.

> Life is a series of problems:
> You are either in one now, you're just coming out of one, or you're getting ready to go into another one.
>
> Instead of thinking of life as hills and valleys-you go through a dark time, then you go to the mountaintop, back and forth think of life like two rails on a railroad track, and at all times you have something wonderful and something challenging in your life.

No matter how wonderful things are, there is always something challenging that needs to be worked on; and no matter how challenging things are, there is always something wonderful to be thankful for.

You can focus on your purposes, or you can focus on your problems.

If you focus on your problems, you're being self-centered (my problem, my issues, and my pain).

One of the easiest ways to get rid of pain is to move the focus off of you and onto others.

Happy moments; Difficult moments; Quiet moments; Painful moments; Every moment, Life is a journey. (Adapted from Rick Warren's interview with Paul Bradshaw..Rick Warren is the author of PURPOSE DRIVEN LIFE and pastor of Saddleback Church in Ca., personal communication 03/25/09)

Table 1

Demographic Information

Pseudo-nym	**Ann**	**Ed**	**Sara**	**Patty**	**Scott**	**Erin**	**David**	**Rose**	**Xavier**	**Grace**	**Steve**
City of Residence	St. Cloud	St. Cloud	Monticello	Montrose	Montrose	Sauk Rapids	Sauk Rapids	Maple Grove	Maple Grove	St. Michael	St. Michael
Marital status	2nd M 1992	1st M 1992	1st M 1997	1st M 1999	1st M 1999	1st M 1991	2nd M 1991	1st M 1991	1st M 1991	1sr M 1986	1st M 1986
Age of interviewee	03/17/65	11/21/68	11/03/65	02/3/68	07/15/68	08/01/53	08/26/48	07/20/51	07/08/56	06/12/64	10/14/62
Employment Status	FT – telecommunications	Laid off	FT – job training Husband stays home	FT - administrator	FT – sales (works from home)	Home maker	Over the road driver	FT – Nurse Practitioner	FT – RN	FT – RN	FT – executive
Income	30-60K	30-60K	30-60K	80-100K	80-100K	30-60K	30-60K	100,000+	100,000+	100,000+	100,000+
Minnesota Native	Yes	No, California 1992	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No, S. Dakota 1987	No, Colorado 1977
Disability status	Depression (SAD) Hearing Impaired Dyslexia Didactic Memory	Diabetes Cyclothymic Disorder Anxiety Disorder	None, suspects husband has Asperger's	Thyroid Disease Esophagus disorder	ADD Believes has Asperger's	Depression	Depression Alcoholism	ADD	None	Chronic neck injury (result of abuse from child)	None

Tale 1 (continued)

Pseudo-nym	**Ann**	**Ed**	**Sara**	**Patty**	**Scott**	**Erin**	**David**	**Rose**	**Xavier**	**Grace**	**Steve**
Education	A.A.	11th – G.E.D.	B.A.	H.S. Diploma	A.A.	B.A.	H.S. +2 yrs trade school	Master's in Nursing	B.S./ 2 year RN	B.S.	B.S.
Religious Affiliation	Wicken	Pantheist Buddhist Discordia	Protestant	Lutheran	Catholic	Lutheran	Lutheran	None	None	Catholic	Lutheran
Race	Lakota/ Caucasian	Cherokee/ Caucasian	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian

Table 2

Care Giver Strain Tool

	Yes=1	No=0
Sleep is disturbed (e.g., because _____is in and out of bed or wanders around at night)		
It is inconvenient (e.g., because helping takes so much time or it s a long drive over to help)		
It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)		
It is confining (e.g., helping restricts free time or cannot go visiting)		
There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)		
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)		
There have been other demands on my time (e.g., from other family members)		
There have been emotional adjustments (e.g., because of severe arguments)		
Some behavior is upsetting (e.g., because of incontinence; _____has trouble remembering things; or _____accuses people of taking things)		
It is upsetting to find_____ has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)		
There have been work adjustments (e.g., because of having to take time off)		
It is a financial strain		
Feeling completely overwhelmed (e.g., because of worry about _____; concerns about how you will manage)		
TOTAL SCORE (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.)		

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APPENDICES

APPENDIX A

Sample Letter Recruiting Volunteers

2008

Dear Parent

My name is Richelle Kramer. Like many of you, I am the parent of a child with an Autism Spectrum Disorder. I am also a graduate student at St Cloud State University, working on a Master of Social Work degree. Part of my program involves a research project also known as a thesis.

I am writing my thesis on the impact of Asperger's Syndrome on the family system. I am looking for families who are willing to talk with me about the joys and challenges of having a family member with Asperger's Syndrome. I want to hear your story.

Interviews will take approximately one hour and will be conducted between January and March of 2009. I would be happy to come to your home, or meet with you in a convenient location. Names and identities will be kept confidential. Information obtained will be used to identify themes and patterns that are experienced in our special families. I hope to gain insight into how your family has been impacted by having a child on the spectrum and use that information to advocate for improved supports for families living with Asperger's Syndrome.

If you are interested in participating, please contact me by cell phone at 612-269-9052 or e-mail at krri0701@stcloudstate.edu. Through awareness, education, and by working together, we can enhance the lives of our children. Thank you for your help.

Sincerely,

Richelle Kramer

APPENDIX B

Sample Consent Form

What impact does Asperger's Syndrome have on the family?

Informed Consent

You are invited to participate in a research study exploring the impact Asperger's Syndrome has had on your family. You were selected as a possible interview participant because you indicated that you have a family member diagnosed with Asperger's Syndrome. You voluntarily agreed to share your story. Between ten and twenty individuals will be interviewed.

This research project is being conducted by Richelle Kramer to satisfy the requirements of a Master's Degree in Social Work at St. Cloud State University, class of 2009.

Background Information and Purpose

The purpose of this study is to gain a broader understanding of the joys and challenges your family has experienced in caring for a child with Asperger's Syndrome. It is hoped that by gaining a better knowledge of how this disability impacts the family, more successful interventions and supports will be created resulting in increased positive outcomes for the families and children living with this disability.

Procedures

If you decide to participate, you will be asked to share your personal story with this researcher. You will do this by completing an assessment tool and participating in a free flowing interview/conversation about your experiences in caring for a family member with Asperger's Syndrome. There will be a total of one, digitally recorded interview. The interview will take approximately one hour.

Risks

Potential risks include possible discomfort in your emotions in sharing your very personal story. It may be inconvenient to your schedule in making time for an interview. Be assured that you will not be judged in your parenting style or on your perceptions about your situation. Interviews will be arranged based upon your availability. You may withdraw your consent to participate in this study at any time and without reason. If at any time the researcher or interviewee feels unsafe, the interview will be ended and the information obtained will be destroyed and excluded from the study.

Benefits

Sharing difficult struggles with others can be therapeutic. Knowing that your story could benefit your family as well as others is a benefit to all who live with or know a family caring for a child with Asperger's Syndrome.

Confidentiality

Information obtained in connection with this study is confidential and will be reported as aggregated (group) results. No individual results or information that can be identified with you will be revealed. All raw data and any identifying information will be stored in a secure location and will be destroyed when the study is complete. Although the names of individual subjects will be kept confidential, there is a possibility that you may be identifiable by your comments in the published research. You will have an opportunity to review the text and withdraw comments prior to publication.

Research Results

Upon completion, my thesis will be placed on file at St. Cloud State University's Learning Resources Center. I will be happy to share my research results with you upon your request.

Additional Resources
If you'd like to know more about Autism and Asperger's Syndrome, you may be interested in the following websites: www.autism-society.org, www.ausm.org, www.aspergersyndrome.org

Contact Information
If you have questions right now, please ask. If you have additional questions later, you may contact me at 612-269-9052 or krri0701@stcloudstate.edu or my advisor; Gary Whitford at gswhitford@stcloudstate.edu. You will be given a copy of this form for your records.

Voluntary Participation/Withdrawal

Participation is voluntary. Your decision whether or not to participate will not affect your current or future relations with St. Cloud State University or this researcher. If you decide to participate, you are free to withdraw at any time without penalty.

Your signature indicates that you have read the information provided above and have decided to participate. You may withdraw from the study at any time without penalty after signing this form.

Signature ____________________ date ____________________

Compensation/Expenses

There is no fee to participate in this study. Participation will be at your own expense and every effort will be made to limit your travel needs to complete the interview.

New Information

I will inform you of any significant new findings developed during the course of this research that could influence your willingness to continue participating.