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Challenges of forming a registered student organization for students with Asperger's syndrome or high functioning autism

Jennifer L. Smith

Eastern Illinois University

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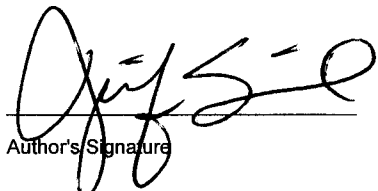
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The Challenges of Forming a Registered Student Organization for
Students with Asperger's Syndrome or High Functioning Autism

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Jennifer L. Smith

THESIS

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF

Master of Science in College Student Affairs

IN THE GRADUATE SCHOOL, EASTERN ILLINOIS UNIVERSITY
CHARLESTON, ILLINOIS

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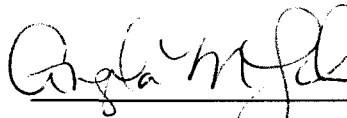
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The Challenges of Forming a Registered Student Organization for Students with Asperger's
Syndrome or High Functioning Autism

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Department of Counseling and Student Development

Eastern Illinois University

Charleston, IL

August, 2012

ABSTRACT

Autism is a complex disorder, affecting a person's ability to socialize, process information, and communicate effectively. Often, persons with autism struggle with sensory system deficits that compound their isolation. As college campuses welcome an increasing number of students with Asperger's Syndrome (AS) or High Functioning Autism (HFA), student affairs professionals must learn to adapt their skills to challenge and support this population. Student affairs professionals instinctively encourage students to form student organizations (RSO) and to be involved on their campuses to ensure enriching learning experiences. It is important for student affairs professionals to be aware of the effects of autism on an individual's level of comfort with being involved in campus life in the same way that a neurotypical student is able to be. Through qualitative interviews with adults with AS or HFA who had attended college, it was revealed that some persons with AS or HFA are uncomfortable in group settings but are in need of, and receptive to, receiving other forms of social supports. Moreover, some students with autism are eager to participate in an RSO for their population, but have differing opinions regarding the purpose, function, and format of such an organization. When establishing social groups for students with AS or HFA, it is important that a neurotypical person with an understanding of autism moderate group meetings, and that confidentiality is emphasized to assuage concerns regarding stigmatization.

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First and foremost, I would like to thank my committee, Dr. Rick Roberts, Dr. Angela Yoder, and Ms. Jill Fahy M.A., CCC-SLP, for their support, dedication, encouragement, and commitment. Each committee member spent countless hours of their own time guiding me through this process to make this project something that I can be proud of.

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as encouragement that kept me striving to do more, be more, and write more. Having Ms. Fahy in my life has improved it considerably, and her kindness and compassion toward me and my family are appreciated more than I can say.

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It is never easy to open up to a stranger, especially when you are speaking about your own personal struggles and deficits. Each of the participants in this study are amazing human beings who placed their trust in me and provided incredible insights that were practical, wise, and at times, incredibly moving. I thank each of them from the bottom of my heart and I wish each of them peace and prosperity throughout their lives.

Each of these interviews occurred because an acquaintance of mine introduced me to the participants, and for this I am so grateful. Through my research, I discovered that each of the participants in this study was successful in life because of those who love them, advocated for them, and fought for their futures. In some cases, loved ones encouraged and reminded the participant to be interviewed. These people have my unending admiration.

I could not have accomplished this task without the encouragement and humor of fellow members of the "old lady cohort," as well as several of the traditionally aged graduate students that I had the good fortune of attending school with. In particular, I owe a debt of gratitude to Jennifer Elliott and Jessica Wright, who I am blessed to have as friends.

My parents sent me pens, paper, highlighters, and pencils at the start of my first semester in graduate school, just as they would have for any other school year in my life, and joked with me that I needed to take a picture of myself in front of the house before I left for my first class. I did, but it caught me at an unflattering angle (and this was before I gained my grad school weight!), so I never sent it. I realize now that I need to, for they will love it anyway. The unconditional love and pride my parents feel for me is one of my life's greatest treasures, and their faith in me is everything.

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And last, but certainly not least, I would like to thank my sons and husband, who tolerated a dirty house, processed foods, and a distracted mother throughout this process. It was a true delight to me when my children became excited for me and my research, and I hope my constant work on the laptop inspires them to never stop learning throughout their lives. I love you guys!

DEDICATION

I humbly dedicate this work to my two sons Brandon and Blake, two very different people who inspire and teach me for more than I could ever hope to in return. It is through Brandon that I acquired an understanding and appreciation of people on the autism spectrum, and it is through Blake that I grew to understand what acceptance and unconditional love truly are. I wish you both much love and learning throughout your lives.

The author Paul Collins once said, “Autists are the ultimate square pegs, and the problem with pounding a square peg into a round hole is not that the hammering is hard work. It's that you're destroying the peg.” In that spirit, I would like to dedicate this research to people on the autism spectrum who fight that metaphorical hammer every day of their lives. My hope is that anyone who reads this research will come to understand that each person on the spectrum has a unique character, distinct needs, and profound thoughts and feelings.

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CHAPTER I

Introduction

Overview of Autism Spectrum Disorders

Autism Spectrum Disorder is a genetic disorder (Wing & Gould, 1979) estimated to occur in 1 in 88 children in the United States (Center for Disease Control, 2012). The disorder is characterized by a qualitative impairment in social interaction, a qualitative impairment in communication, and restricted, repetitive, and stereotyped patterns of behavior, interests, and activities (American Psychiatric Association, 1994). Autism is referred to as existing along a spectrum due to its varying degrees of symptomology, which greatly influences the functional ability of the person affected. According to the *Diagnostic and Statistical Manual of Mental Disorders: DSM-IV* (2010), persons affected by Autism display impairments in the use of nonverbal behaviors (such as eye-to-eye gaze, facial expression, body posture, and gestures) to regulate social interaction. They fail to develop peer relationships, and display an encompassing preoccupation with an interest that is abnormal either in intensity or focus. A person with Autism will have an inflexible adherence to specific, nonfunctional routines, and possibly stereotyped and repetitive motor mannerisms (such as hand flapping or rocking).

Asperger's Syndrome

Asperger's Syndrome (AS) is categorized as a subgroup within the Autism Spectrum and currently has its own diagnostic criteria in the *Diagnostic and Statistical Manual of Mental Disorders: DSM-IV*. It is characterized by Attwood (1998) as having core features of "a lack of social skills, limited ability to have a reciprocal conversation and an intense interest in a particular subject" (p. 13). Although individuals with AS display normal cognition, a pattern of prefrontal and frontal lobe deficits is also present which affects executive function (decision-

making, problem solving, judgment, working memory, and planning), as well as motor function and impulse control (G. Richard, personal communication, November 30, 2011). Bolick (2004) described practical characteristics of Asperger's Syndrome as:

- Awkwardness in communication, despite strong vocabulary and grammar
- Difficulty in "reading" the behavior of others
- A preference for predictability
- A tendency toward specific and intense interests
- (Sometimes) inefficient organization and productivity despite strong intellectual abilities
- (Sometimes) challenges in integrating sensory information
- (Often) clumsiness
- (Sometimes) problems in regulating anxiety or mood. (p. 13).

High Functioning Autism

The term "High Functioning Autism" (HFA) is often used to represent an additional subcategory of Autism, although it is not included within the *DSM-IV* as a formal diagnosis. Eisenmajer, et. al (1996), Eisenmajer, et. al (1998) and Howlin (2003) found that persons considered to have HFA displayed early delays in language development, whereas persons with AS had no such delays. According to G. J. Richard (2011), a person is considered to have HFA if he or she displays normal cognition (an I.Q. of 70 or above), presents linguistic challenges affecting auditory perception, language and speech production, and memory association, and demonstrates characteristics typical of Autism Spectrum (e.g., sensory system deficits, ritualistic, stereotypic behaviors) (personal communication, November 30, 2011).

Debate Regarding Asperger's Syndrome and High Functioning Autism Distinction

With the projected publication in 2013 of the *Diagnostic and Statistical Manual of Mental Disorders: DSM-V*, the American Psychiatric Association currently intends to remove AS as a diagnosis, and will consider those with the previously defined symptoms of AS as having "Autistic Disorder." There is much debate in the scientific community regarding whether AS is a separate and distinct disorder from HFA. In their development of a screening questionnaire for AS and HFA for school-aged children, Ehlers, Gillberg, & Wing (1999) emphasize a distinction between AS and other high functioning autism spectrum disorders. However, Fitzgerald & Corvin (2001) performed an analysis of criteria used for diagnosing AS and autism and stated, "Current research data do not convincingly support the separation of Asperger syndrome and the autistic spectrum disorders as distinct disorders" (p. 312).

When conducting a review of existing literature for this study, it was discovered that some researchers made no distinction between AS and HFA (Attwood, 1998, 2008; Bolick, 2004; Graetz & Spampinato, 2008; MacLeod, & Johnston, 2007; Madriaga, 2010; Weidle, Bolme, & Hoeyland, 2006), while other researchers differentiated between the two diagnoses (Barnhill, 2007; Bolick, 2004; Carter, 2009; Grandin, 1996; Hillier, Fish, Cloppert, & Beversdorf, 2007; Jantz, 2011; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000; Muller, Schuler, & Yates, 2008; Rao, Beidel, & Murray, 2008; Rose, & Anketell, 2009; Shtayermman, 2007; Volker et. al, 2010; Wing, & Gould, 1979).

It is acknowledged that each individual with Autism is unique and displays unique symptomology. For the purposes of this study, the diagnoses of Asperger's Syndrome and High Functioning autism were considered to be distinct, and participants were able to identify as being diagnosed with either of the two diagnoses.

Social Challenges of Individuals with Asperger's Syndrome or High Functioning Autism

Persons with AS or HFA are often viewed by other people as different because of their unusual quality of social behavior and conversation skills (Attwood, 1998). They are frequently misunderstood, and the intentions of their actions are misconstrued. According to Attwood (1998), a person with AS “does not seem to be aware of the unwritten rules of social conduct and will inadvertently say or do things that may offend or annoy other people” (p. 31). People with AS or HFA are often confused by the emotions of others and can have difficulty expressing their own feelings. Persons with Autism struggle with Theory of Mind, which is the understanding that other individuals have feelings, beliefs, and desires that differ from their own. According to Attwood (1998):

People with Asperger's Syndrome appear to have some difficulty conceptualizing and appreciating the thoughts and feelings of another person. For example, they may not realize that their comment could cause offense or embarrassment or that an apology would help to repair the person's feelings. (p. 12).

During adolescence, people with AS typically start to become more interested in socializing with others while simultaneously becoming aware of their differences. They want to relate to their peers and to have friends, but do not know how to succeed. When people with AS try to have friends, they are often excluded, teased or ridiculed (Attwood, 1998). Graetz and Spampinato (2008) stated that most adolescents with AS want to socialize with their peers but lack the ability to do so naturally, and find the experience overwhelming and frustrating. The emotional changes of adolescence are often delayed and prolonged in a person with Asperger's Syndrome, and when combined with a delayed acquisition of social skills, the affected person may not have a close and intimate relationship until much later than his or her peers (Attwood,

1998). Arthur (as cited in Prince-Hughes, 2002) described how he is affected by Asperger's Syndrome, "It's so difficult when you see the world as it is but you don't really feel a part of it" (p. 80).

Muller, Schuler, and Yates (2008) studied the perspective of adults with AS and found that many reported feelings of intense isolation. Several participants in their study reported having no real friendships. They did not understand how to initiate social interactions and reported experiencing tremendous anxiety when attempting to do so. Participants indicated an interest and desire for greater emotional intimacy and social connectedness, a desire to contribute to their communities, and made efforts to develop greater social and self-awareness in order to compensate for the effects of their Autism.

Frequently, people with Autism suffer from sensory processing issues such as hyper or hyposensitivity with each of the five commonly known senses (visual, auditory, tactile, oral, olfactory), and the two lesser-known senses, proprioceptive (the sense of one's body in relation to the world around it) and vestibular (the sense of balance and movement). For example, a person with Autism may be easily agitated in a crowd, could be extremely sensitive to certain sound frequencies (including those emitted by fluorescent lighting), may be very uncomfortable sitting still, may feel a need to have deep pressure applied to the body (while light touch is simultaneously painful), may feel uncomfortable in a large open space, have an uncontrollable need to hum, or may be unable to focus on a specific topic when many items are presented on a SMART board. According to Heller (2002), "Perhaps no one is more victimized by sensory defensiveness than the autistic" (p. 88). These sensory sensitivities make it very difficult for an affected person to participate fully in typical daily activities.

College Students with Asperger's Syndrome or High Functioning Autism

Many people with Autism are able to attend college but struggle, as collegiate life presents social and academic challenges that had not been encountered previously by the individual. Graetz and Spampinato (2008) stated that students with AS are confronted with challenges that do not exist for the typical student. Deficits in communication and socialization combined with narrowed interests and sensory sensitivities affect students with AS ability to adapt to the typical day in college. A greater number of students with AS are now expecting to attend college and many of these students naively expect college to be a place where they will excel and easily make friends (Graetz & Spampinato, 2008).

Student affairs practitioners on college campuses are challenged when working with students with AS or HFA. Blake (1996) described student affairs practitioners as “often drawn to the subjective, experiential aspects of life, toward events and problems in their particularity, and toward accomplishing things through others, frequently by organizing people into groups” (p. 5). Student affairs practitioners often rely on interpersonal interaction to challenge and support students, yet students with autism interact in ways that are very different than the typical student these practitioners are familiar with. Student affairs practitioners are dedicated to encouraging students to be involved and engaged in order to enhance their learning experiences, yet the very nature of autism causes a student with this disorder to struggle socially, as they are often anxious in crowds or groups and struggle to sustain a spontaneous conversation or express their anxieties.

Astin (1999) stated “the highly involved student is one who, for example, devotes considerable energy to studying, spends much time on campus, participates actively in student organizations, and interacts frequently with faculty members and other students” (p. 518). Student involvement is important, Astin stated, because “the extent to which students can

achieve particular developmental goals is a direct function of the time and effort they devote to activities designed to produce these gains” (p. 522). Astin argued that all development, whether it is in the classroom or outside of the classroom, should involve interpersonal interaction, including discussions with faculty and peers, and the formation of commonality groups, in addition to reading, writing, practicing, and studying. The nature of autism makes it extremely difficult for a student with the disorder to be involved to the level that student affairs practitioners believe necessary for a truly enriching collegiate learning experience.

Rationale and Purpose

As college campuses welcome an increasing number of students with AS and HFA, student affairs professionals must learn to adapt their skills to challenge and support this population. Student affairs professionals instinctively encourage the formation of social groups and campus involvement to ensure an enriching learning experience, and it is important for these professionals to be aware of the effects of autism, and whether or not an individual with autism is comfortable being involved in campus life in the same way that a neurotypical student is able to be.

Attwood (2008) stated, “Student life is not all academic study and the person with Asperger’s syndrome will probably want to make friends and participate in student social activities” (p. 294). Grandin (1986), Holliday Willey (1999), and Prince-Hughes (2002) discussed the importance of finding other people who were similar to them while they attended college. Bebbington and Sellers (as cited in Attwood, 1998) found common issues that adults with AS faced included feelings of isolation and the need to know that there are other people like themselves. Attwood (1998) stated, “Psychological research has established that similarity is one

main criteria for selecting friendships. This has led many people with Asperger's Syndrome to find friendships with other people who have the same diagnosis" (p. 53-54).

Willey (1999) offered advice for people with AS who are attending college, "Ask your counselor if the university has, or could establish, a friendship group for people with AS and related syndromes" (p. 132). The feelings of isolation that a person with Asperger Syndrome or Autism has can be reduced through contact with support groups (Attwood, 1998). Bolick (2004) stated, "many students with AS benefit from a formal or informal 'Circle of Friends' (individuals who come together regularly to help the student with particular challenges)" (p. 176).

In a qualitative study conducted by Muller, Schuler, and Yates (2008), adults with AS stated they preferred social supports that included joint focus, shared interest, and structured and facilitated social activities. They stressed the importance of membership within Autism-related groups, which provided a joint focus and enabled them to meet others like themselves, but agreed that it was usually necessary for someone else to organize and maintain any group.

Graetz and Spampinato (2008) make several recommendations for assisting students with AS in the college process. Among them are: talking to other students with AS who attend or attended college, identifying coping skills and supports that are in place at the institution of choice, and encouraging group meetings for people with Asperger's Syndrome. Graetz and Spampinato stated that many people with AS seek the companionship of others with AS, and label themselves as "aspies," calling those without the disorder "NTs," or "neurotypicals."

In 2006, Troy Corley, the mother of a college student with AS started a social support group for adolescents with the disorder called "Asperger's Support for Adolescents Plus" (ASAP) (Lee News Service, 2011). The club does not provide therapy and purposefully meets in locations that are non-clinical in appearance. The moderator of the group allows participants to

be themselves, and only intervenes if someone is being hurtful to another member. In 2010, a chapter of ASAP was formed at American River College. A disabilities counselor at the college observed that the students with AS formed tight subgroups based on their common interests. The participants in the ASAP program reported feeling comfortable with each other and free to be themselves without being judged. One participant's mother reported that her son was able to navigate socially at his college largely due to his participation in ASAP.

While it is important that students with AS and HFA connect, the inherent features nature of the disorders makes it difficult to do so. Jantz (2011) stated that the very nature of AS makes it difficult to maintain a group. The majority of participants are completely absorbed in their topics of interest and are unable to interact with others, including those with Asperger's Syndrome. Prince-Hughes (2002) wrote of the difficulty that people with Autism have with organizing groups, stating that the symptoms of autism (such as difficulty coping in social situations, aversion to direct eye contact, and difficulty quickly responding conversationally), prevent many people with autism from finding each other and organizing sustainable real-time meetings.

Registered Student Organizations

The primary researcher explored post-secondary educational institutions in the state in which the study was conducted and discovered the following common practical advantages to organizing and establishing a registered student organization (RSO) on a college or university campus: use of institution facilities for meetings and events, the privilege of sponsoring activities and events, use of institution name in association with the RSO, access to institution resources and equipment, support from student life office, and use of organization fund accounts. Establishment of an RSO also opens the door to potential funding from the institution or a national affiliation.

A search of colleges and universities in the state in which the study was conducted indicated that establishment of an RSO typically requires submission of an application, the development of a constitution, the election of 2-5 officers, a minimum member requirement (5-10 members), an established meeting schedule, provisions for dues and other revenue, and the obtainment of a faculty or staff advisor.

Purpose of the Study

The purpose of the present phenomenological study was to observe the formation of a student organization for university students with AS or HFA. In addition, the opinions of adults with AS or HFA regarding student organizations were obtained to gain valuable insight from their experiences. In particular, insight from study participants may benefit student affairs or disability services professionals when considering the formation of a group on their own campuses.

Research Questions

The following research questions were developed to guide the present study:

1. What are the perceptions of students with Asperger's Syndrome or High Functioning Autism when invited to organize a registered student organization?
2. What challenges and/or issues emerge as the registered student organization is being formed?
3. What are the perceptions of adults with Asperger's Syndrome or High Functioning Autism who have been to college regarding the establishment of student organizations for students with Autism?
4. Do age and maturity affect a person with Asperger's Syndrome or High Functioning Autism's opinion regarding the joining of a group?

Significance of the Study

Research regarding organizations for students in post-secondary education with HFA or AS is limited. The present study seeks to qualitatively study the formation of a student group using phenomenological methods and qualitative interviews. Findings of this study will enhance understanding of the collegiate experience for those with AS or HFA, and will provide a valuable framework for student affairs and disability services professionals regarding the successes and challenges of establishing a student organization for a population that struggles with socialization but desperately needs contact with others who have the same disorder who are sharing the same experiences.

Limitations of the Study

1. The very nature of Asperger's Syndrome and Autism will make it difficult to interpret participant thoughts and feelings, as the disorder causes them to struggle with expression. Many participants may not voice their opinions during the process of group formation because of their struggles with communication and social anxiety. Depending on the level of functionality of the individual, spontaneous conversation and the answering of questions is extremely difficult. A participant may struggle to process the question being asked and to formulate an answer to the question, resulting in a lack of response. In addition, persons with autism struggle with nonverbal expression, making it difficult to fully assess participant levels of attention, participation, and emotion.
2. There are a small number of people with Asperger's Syndrome available for qualitative interviews. Participants in this study cannot be considered to represent all students with Asperger's Syndrome.

3. There are a small number of people with High Functioning Autism available for qualitative interviews. Participants in this study cannot be considered to represent all students with High Functioning Autism.
4. The study was conducted at one institution only, and it is impossible to conclude that the exact same phenomenon will occur at another institution.
5. Only those who respond to the invitation to participate in the study will be included in the study, therefore, the voices of those who are hesitant to participate in a research study will not be heard.

Definition of Terms

1. **Asperger's Syndrome:** a subgroup within the Autism Spectrum, it is characterized by Attwood (1998) as having core features of "a lack of social skills, limited ability to have a reciprocal conversation and an intense interest in a particular subject" (p. 13). A person with AS displays normal cognition, and presents with deficits in executive function (decision-making, problem solving, judgment, working memory, and planning), as well as motor function and impulse control (G. Richard, personal communication, November 30, 2011).
2. **Autism:** The *Diagnostic and Statistical Manual of Mental Disorders: DSM-IV* (2010) states that persons affected by Autism display impairments in the use of nonverbal behaviors to regulate social interaction. They fail to develop peer relationships, and display an encompassing preoccupation with an interest that is abnormal either in intensity or focus. A person with Autism will have an inflexible adherence to specific, nonfunctional routines, and possibly stereotyped and repetitive motor mannerisms.

3. High Functioning Autism (HFA): The term “High Functioning Autism” is often used to represent an additional sub-category of Autism, although it is not included within the *DSM-IV* as a formal diagnosis. A person is considered to have HFA if he or she displays normal cognition (an I.Q. of 70 or above), presents linguistic challenges affecting auditory perception, language and speech production, and memory association, and demonstrates characteristics typical of Autism Spectrum (e.g., sensory system deficits, ritualistic, stereotypic behaviors) (G. Richard, personal communication, November 30, 2011).
4. Neurotypical: A term used to describe persons who do not have Autism.
5. Registered Student Organization (RSO): An RSO is an institutionally-sanctioned student group.
6. Student Affairs Practitioner: the National Association of Student Personnel Administrators (NASPA) defines student affairs practitioners as:

People who work in student affairs provide services, programs, and resources that help students learn and grow outside of the classroom. Some things that student affairs professionals do for students every day include:
 - Enhance student learning
 - Guide academic and career decisions
 - Mentor students
 - Promote leadership skills
 - Counsel students through crises (“Careers” section, 2012)

Summary

Autism is a complex disorder, affecting a person's ability to socialize, process information, and communicate effectively. Often, persons with autism struggle with sensory system deficits that compound their isolation. Despite the challenges of living with autism, many people with AS or HFA are able to attend college. Many scholars and people with autism who attended college have emphasized the importance of group membership with others who are affected by the disorder. The current study sought to observe the formation of such a group in a university setting and to obtain the knowledge and opinions of adult with the disorder regarding student groups in order to educate student affairs practitioners to serve this population in the best way possible.

CHAPTER II

Review of Literature

A review of literature was conducted regarding relevant experiences of people with autism as well as the effectiveness of group membership in general. The study focused on six areas: Support Groups for People Diagnosed with AS or HFA, Effectiveness of Student Organizations for Other Marginalized Populations, Comorbid Disorders Including Depression and Anxiety, Peer Victimization, Narratives of People with Asperger's Syndrome or High Functioning Autism, and Challenges and Supports for College Students with AS or HFA. The first two areas of the review of literature focused on the effectiveness of group membership. The last four areas of the review of literature focused on the Asperger's Syndrome and High Functioning Autism experience, with emphasis on comorbid mood disorders, social challenges, interaction with peers, and collegiate experiences.

Support Groups for People Diagnosed with AS or HFA

Research conducted regarding participation in support groups for persons with AS or HFA has shown that there are desirable outcomes for group participants. Studies focused on the effects support groups might have on participants' social skills, emotional states, and symptomology.

Two studies revealed that participation in support groups improved social skills in participants diagnosed with AS or HFA. Weidle, Bolme, & Hoeyland (2006) studied whether participation in a support group would improve social functioning, communication skills, self-confidence and sense of identity among young adults with Asperger's Syndrome, and Hillier, Fish, Cloppert, & Beversdorf (2007) reviewed the efficacy of a social and vocational skills support group for adolescents and young adults diagnosed with an autism spectrum disorder.

Weidle, Bolme, & Hoeyland, (2006) developed three therapeutic groups for adolescents with Asperger's Syndrome, and monthly sessions were conducted during an 11-month period. A consumer satisfaction survey for participants and their parents was conducted, and half of the parents recorded improvement of identity and self-confidence in their adolescent group participant. Participants were not initially interested in joining the groups, but Weidle, et al. found participant motivation had increased considerably.

Hillier, Fish, Cloppert, & Beversdorf (2007) administered the *Empathy Quotient* to participants before and after the social and vocational skills support group program that was studied. Meetings were observed and changes in frequency of contributions made by group members over the course of the program were examined. Hillier et al. found that responses to the *Empathy Quotient*, which measured participants' ability to empathize, showed significant differences before and after participants completed the program ($p = .012$). A Wilcoxon signed ranks test revealed that more contributions were made by group members toward the end of the program than at the beginning ($p = .028$). In feedback sessions with participants and their parents, participants reported that they increased their own efforts to interact with other persons socially, made friends with other group members and benefitted from interaction with others with Autism by discussing challenging personal issues with others who can relate. Participants' parents reported that their sons and daughters showed greater interest in social interaction, increased enthusiasm about attending meetings, more pride in their appearance, and took more initiative in finding jobs.

A study conducted by Rose & Anketell (2009) examined the effects group participation may have on emotional states as well as social abilities of persons diagnosed with autism. Participants' parents rated their children's difficulties regarding anxiety, depression, aggression,

withdrawal, self-esteem/confidence, and social and communication difficulties via a non-standardized questionnaire prior to the commencement of the group, at the end of the group, and 6 months after group ended. Qualitative data was collected via a participant parent focus group. Participants completed evaluations after every group session, rating how useful they found the session. A number of children were rated by their parents as “better” on at least one area of difficulty after the group completed. The majority of improvement was in social difficulties, communication difficulties and withdrawal. The majority of parents and participants rated the sessions as either “very useful” or “useful”. Parents mentioned a number of positive aspects of the social skill groups, including forming friendships and fostering “normal” socializing experiences in a controlled environment with “like” peers, which they reported as invaluable. Rose & Anketell concluded that “there is sufficient evidence to suggest that this initiative should continue” (p. 140).

Two studies were performed to measure the effects group participation has on the emotional state of participants diagnosed with AS or HFA. Jantz (2011) studied the efficacy of support groups in reducing loneliness for adults with Asperger’s Syndrome, and MacLeod & Johnson (2007) performed an individual case study of a woman with AS who participated in a support group for adults with a diagnosis of Autism Spectrum Disorder.

Jantz (2011) interviewed participants regarding their perceptions of, and participation in, support groups. Participants also completed The *Autism-Spectrum Quotient*, and the *UCLA Loneliness Scale*. The mean participant score for the *UCLA Loneliness Scale* was 58.37 (by comparison, in a recent large-scale study the mean for students and nurses was 40, the mean for the elderly was 32, and the mean for teachers was 19), and participants with a higher *Autism-Spectrum Quotient* score had a higher loneliness score. Jantz discovered there was no association

between the number of months in an Asperger's Syndrome group and the loneliness score, but that participants in the study believed supports groups were useful overall. Participants indicated they wanted a sense of belonging, a place to learn social skills, and a forum for learning from others' experiences with Asperger's Syndrome, and were most likely to seek a support group for social skills and interaction, information and advice, and because they were encouraged to attend by someone else. Several members stated they would have liked their groups to have a more social focus, and that members be grouped by their similarities (age, more even gender ratio, life situation). A number of participants indicated that support groups must be moderated by a facilitator in order to ensure that everyone has the opportunity to speak, and that group meetings are structured, with group rules clearly explained.

The participant in MacLeod & Johnson's (2007) individual case study stated that she gained comfort and reassurance from the support group that she participated in, and that she was not as anxious when she participated in the group as she typically was in social settings because "at the discussion group I could just socialise (sic) and not have to worry about getting it wrong" (p. 86). It was noted that the participant felt part of a common group for the first time in her life, and that peer support and sense of belonging were very valuable to her. Prior to joining the group, the participant stated she was depressed and suicidal about her condition, although depression was not apparent from her diagnostic assessment or her discussion group evaluations. MacLeod & Johnson stated that this is significant, and "highlights the need for us to improve both our assessment processes and the accessibility of support" (p. 87).

Effectiveness of Student Organizations for Other Marginalized Populations

Several studies have been performed to evaluate the effectiveness of student organizations for students who identify with marginalized populations. Schuch (2010) studied

the effects involvement in Lesbian, Gay, Bisexual, and Transsexual (LGBT) had on students at a small Midwestern university; Maina, Burrell, & Hampton (2011) studied students of color who successfully completed college programs on a predominately White campus while coping with race related stress; McKinney (2009) investigated whether events held by a student organization that aimed at increasing awareness of mental illness had an impact on stigma and attitudes toward seeking mental health services; and Talbert, Larke, Jr., & Jones (2000) chronicled the success of the Minorities in Agriculture, Natural Resources, and Related Sciences (MANRRS) national society, which fostered partnerships between college students and professionals.

Schuch (2010) discovered that the primary benefit of membership in an LGBT organization was the access to other LGBT students, and that active LGBT group members felt more comfortable with their sexuality. Students who participated in the LGBT group at the university had a greater knowledge of resources available to them.

Maina, et al. (2011) found that the students of color who successfully completed college programs despite racial stressors had engaged in coping strategies that included supportive social networks. Participants indicated their social networks were composed of peers, professors, campus staff, and upperclassmen. Participants indicated that they actively sought supports and formed social networks themselves. Maina, et al. stated, "Students in this study increased and boosted their ability to succeed in their program by developing social network of friends, professors and members of staff. It is clear they actively sought the supports they needed whether academic or social support. Once they identified the supports they needed, they used them to their own advantage" (p. 9).

McKinney (2009) examined a student organization named Active Minds, which aimed at increasing awareness of mental illness, reducing stigma, and encouraging affected people to seek

treatment. Sixteen Likert-type items from the General Attribution Questionnaire (Corrigan et al., 2001; Corrigan et al., 2002) were administered to participants at the beginning and end of the study in order to measure stigmatizing beliefs and attitudes toward seeking professional help. McKinney found that mean scores for the stigma-related items administered declined significantly for the group of students involved with Active Minds ($p = .002$). The mean scores also indicated that those who participated in Active Minds who had a family member with a mental illness had an even greater reduction of stigma ($p < .001$). However, there were no significant findings regarding students' willingness to seek psychological help after participating in the group.

Talbert, Larke, Jr., & Jones (2000) observed the types of mentoring experiences provided by the MANRRS program, the significance of those experiences, and their impact on students. MANRRS mainly utilized the networking and grooming models of mentoring, and served "as a haven for students to share concerns, experiences, and successes among themselves and with university personnel" (p. 98). Talbert, Larke, Jr., & Jones postulated that MANRRS members benefitted academically through their exposures to positive and successful role models and their networking with other MANRRS members who were in their same courses.

Comorbid Disorders Including Depression and Anxiety

Studies have shown that persons with AS or HFA are often affected by comorbid mood disorders. Several studies utilized rating scales to measure mood disorders in persons diagnosed with autism spectrum disorders and noted correlations between symptoms of mood disorders and of autism.

Hedley & Young (2006) and Barnhill (2001) examined the relationship between depressive symptoms and social attributions in children and adolescents diagnosed with

Asperger's Syndrome. Hedley & Young (2006) administered the *Social Comparison Scale (SCS)*, designed to assess an individual's comparison of self with others, and the *Children's Depression Inventory (CDI)*, a self-rated depressive symptom inventory, to children and adolescents with a diagnosis of Asperger syndrome. Hedley & Young found a significant correlation existed between the *SCS* and the *CDI* total score ($p = 0.001$); therefore, participants who perceived themselves as being more dissimilar to others reported higher depressive symptoms.

Barnhill (2001) investigated the relationship between level of depressive symptoms and social attributions, as well as the relationship between intellectual level and social attributions in adolescents with Asperger syndrome. Participant IQs were collected, and the *Student Social Attribution Scale (SSAS)*; Bell & McCallum, 1995) and the *Children's Depression Inventory* were administered to each participant to measure their perceptions of the causes of their school-related social success and failure. Barnhill found a significant positive relationship between depressive symptoms and ability attributions for social failure ($p < .05$); the more participants attributed social failure to their ability and effort, the higher their depressive symptoms score. Barnhill also discovered that the lower the participant's IQ, the more likely it was that he or she attributed success to chance or task factors, and the higher the participant's IQ, the less likely that he or she attributed success to chance or task factors ($p < .05$). Barnhill concluded:

It is possible that more intelligent individuals with Asperger syndrome are developing an awareness that social life events are not just random or due to luck but may be caused by other factors, such as mutual interest in a shared activity (p. 51).

Several studies have been conducted to determine the prevalence of comorbid disorders in persons with AS or HFA in comparison with the rest of the population. Volker et al. (2010)

compared *Behavior Assessment System for Children Second Edition (BASC-2)* profiles of children with high-functioning autism spectrum disorder and children in a control group; Hill, Berthoz, & Frith (2004) studied existence and extent of difficulties in the cognitive processing of emotions in a group of adults with HFA, and Kim, Szatmari, Bryson, Streiner, & Wilson (2000) conducted a quantitative study of the prevalence and impact of comorbid psychiatric problems among adolescents with HFA and AS.

The *Behavior Assessment System for Children Second Edition (BASC-2)* evaluates clinical and adaptive aspects of behavior and personality. Volker et al. (2010) analyzed *BASC-2* profiles of 62 children with high-functioning autism spectrum disorder (HFASD) and 62 children with no known disability (who were of the same age, gender, and ethnicity). The *BASC-2 Parent Rating Scale-Child (PRS-C)* and the *BASC-2 Parent Rating Scale-Adolescent (PRS-A)* were also completed by a parent of each participant. Volker et al. found that all four *BASC-2 PRS* composites yielded statistically significant differences ($p < .001$) between the HFASD group and the control group. Participants in the HFASD group were far more likely to experience behavioral and emotional problems than participants in the control group.

Hill, Berthoz, & Frith, (2004) administered the *Toronto Alexithymia Scale (TAS-20)* to adults with HFA and to a control group (of similar age and ability) to measure cognitive processing of emotion. The *Beck Depression Inventory (BDI)* was also administered to the same participants to assess levels of depression. *TAS-20* results indicated that the adults with HFA exhibited a significantly higher level of difficulty in emotion processing than the control group ($p < .001$). *BDI* results indicated that 22.2 percent of the participants with HFA were categorized as “clinically depressed”; however, none of the control group participants were. Hill, et al. also

found that 75 percent of the Adults with HFA who participated in the study also exhibited “some degree of depression,” in contrast to 17 percent of the control group.

Kim, Szatmari, Bryson, Streiner, & Wilson (2000) administered a revised version of the *Ontario Child Health Study (OCHS-R)* to parents of adolescents with HFA and Asperger’s Syndrome, and compared results with those of the general population. Kim, et al. found that the adolescents in the sample had clinically relevant scores in several of the measured disorders (including Attention Deficit Hyperactivity Disorder, depression, generalized anxiety, and separation anxiety) at a more frequent rate than the general population. Kim, et al. discovered that adolescents with HFA and AS are also at greater risk of internalizing problems.

Peer Victimization

Several studies have been performed to determine the frequency with which persons with AS or HFA are shunned or abused by their peers, and the effects these behaviors have on those who were victimized. Carter (2009) studied the frequency of victimization and shunning in children and adolescents with Asperger Syndrome; Symes & Humphrey (2010) studied perceived levels of peer acceptance, peer support, and frequency of bullying experienced by adolescents in the secondary education setting; and Shtayermman (2007) examined the level of peer victimization, depressive symptomatology, anxiety symptomatology, and level of suicidal ideation among adolescents and young adults diagnosed with Asperger’s Syndrome.

Carter (2009) administered the *Juvenile Victimization Questionnaire (JVQ)* (Hamby & Finkelhor, 1999) to parents of children and adolescents diagnosed with AS to assess levels of victimization. An instrument consisting of three questions (Little, 2002) which measured the frequency of shunning experienced by study participants was also administered. Carter found that 64.7 percent of the participants had been victimized and shunned by siblings and peers in

some way within the past year. Results were compared to results of an earlier study by Little in 2002, who found that 94 percent of children and adolescents with AS had reported being victimized and shunned. Carter (2009) suggested:

The lower frequency rates of victimization and shunning in this study may be explained by interventions such as school tolerance programs coupled with better understanding of Asperger syndrome. Despite the decrease in victimization, 65% rate of victimization in children with Asperger syndrome remains high (p. 151).

Symes & Humphrey (2010) compared perceived levels of peer acceptance, peer support, and frequency of bullying experienced by adolescents diagnosed with Autism Spectrum Disorder, Dyslexia, and in a control group. Participants completed the *My Life in School Checklist (MLSC)*, which measured frequency of bullying, the *Social Support Scale for Children (SSSC)*, which measured perceived levels of social support, and the *Social Inclusion Survey (SIS)*, which measured levels of perceived acceptance and rejection. Symes & Humphrey found that Adolescents with Autism Spectrum Disorder were significantly more likely to be rejected by their peers ($p < 0.01$), experienced significantly greater frequencies of bullying ($p < 0.05$), and received lower levels of social support from their peers ($p < 0.01$). There was no distinction between the Dyslexia and control groups for any of the variables studied.

Shtayermman (2007) administered questionnaires to adolescents and young adults diagnosed with AS and their parents in order to measure severity of peer victimization, major depressive disorder, generalized anxiety disorder, levels of suicidal ideation, and AS symptomatology. Results of Shtayermman's assessments indicated that many of the participants in the study reported a high level of peer victimization. Young adults had a higher mean level of victimization compared with the adolescents in the study. Twenty percent of participants met the

criteria for Major Depressive Disorder, and thirty percent met the criteria for Generalized Anxiety Disorder. Fifty percent of participants had clinically significant suicidal ideation. Shtayermman also discovered severity of AS symptomatology was negatively correlated with total degree of peer victimization ($p = .001$), relational victimization ($p = .001$), and overt victimization ($p = .001$). There was a strong negative correlation between level of suicidal ideation and severity of AS symptomatology ($p \leq .01$).

Narratives of People with Asperger's Syndrome or High Functioning Autism

Several people with AS or HFA have spoken publicly, published memoirs, or participated in projects that bring attention to the general population about what it is to be autistic and how it affects their lives. Prince-Hughes (2002) gathered a collection of essays written by college students with autism. One essayist, Garry, described how he is affected by AS:

I would like to describe AS, as it seems to me. It was as if I was like a seed frozen in time. The other seeds were growing and developing and I was getting further and further out of step and never looked like catching up. I had no insight into the social conventions which regular people take for granted (p. 2 – 3).

In Prince-Hughes (2002), Jim described how he is affected by Asperger's Syndrome:

Autism, for me, is just the way things are. It means I don't receive and process information in the same manner as other people, not that I am stupid. It means I don't share the general neurotypical population's innate receptive and expressive communication skills; it doesn't mean I am unable to have feelings and emotions or am unable to share those emotions with others (p. 67).

According to Attwood (1998), persons with AS are often misinterpreted as being uncaring. When referring to college students with autism, Prince-Hughes (2002) states that,

“contrary to popular misconceptions, (they) care deeply about connection” (introduction).

Robison (2011) wrote of the misconceptions others had regarding his ability to feel emotions:

‘Don’t worry, he doesn’t even notice’ was a common refrain when people talked behind my back. Well, let me assure you, I may not have been able to read from people’s subtle clues their thoughts and feelings, or their expectations of me, but I absolutely noticed when they rejected or disregarded me, and I still do. I may seem robotic and mechanical sometimes, but there is nothing mechanical or cold about my internal feelings. I am just as sensitive as anyone to snide remarks and criticism. I cried inside fifty years ago, and I still do today (p. 86).

Muller, Schuler, & Yates, (2008) qualitatively studied the perspectives of adults with AS and other high-functioning autism spectrum disorders regarding social challenges and supports. Participants discussed their social experiences with the researchers and reported feelings of intense isolation. Several participants reported having no real friendships. Participants did not understand how to initiate social interactions and attempting to do so was a source of tremendous anxiety. Muller, Schuler, & Yates found that participants longed for greater emotional intimacy and social connectedness, had a desire to contribute to their communities, and made efforts to develop greater social and self-awareness in order to compensate for the effects of their autism.

Challenges and Supports for College Students with AS or HFA

Grandin (1986) wrote of her transition to graduate school:

. . . I realized I was suffering from the same old syndrome – the lack of familiar surroundings, familiar students and teachers, familiar classes. I wasn’t worthless; I was simply reacting, as a typical autistic individual, to a new environment, new people, and new courses of study. I suffered terrible colitis attacks (p. 121).

Persons with AS or HFA are able to attend college, but face many challenges. Transition and change can be difficult for persons with these disorders. In addition, persons with AS or HFA struggle to adjust to the physical environment of college while attempting to meet greater academic expectations. The stress of the transition to college, combined with the greater expectation for independence, and new academic and social demands can lead to the development of depression or an anxiety disorder in a student with AS or HFA (Attwood, 2008). Attwood (2008) stated that the reason students with AS fail or withdraw from a course is more likely to be related to stress than lack of ability or commitment. Prince-Hughes (2002) wrote, "many brilliant students find the university a formidable mixture of overwhelming sights and sounds, full of change and disruption, and dependent upon social matrixes that are utterly mystifying. They quit university, never to return" (introduction).

Bolick (2001) stated that the social aspect of collegiate life presents the most challenges for a person with AS:

They may have trouble tolerating the habits of roommates or floor-mates. They are often distressed by the rule violations ("Quiet hours start at ten. What is she doing with her stereo blasting?"). They can be overwhelmed by the sexuality of their peers or by the presence of alcohol or drugs (p. 176).

Madriaga (2010) studied university students with AS and their use of campus spaces and found each experience differed because of the variety of participant's sensory issues. Several participants desired social interaction but were restricted by their inability to enter typically social university spaces without triggering anxieties or sensory hypersensitivities. Over half of the respondents identified orientation programs, the local student union pub, and the library as inaccessible and anxiety-provoking places because of the crowded nature of each location or

event and the noises associated with them. As a result, these respondents were socially isolated from their peers. One participant found isolation comforting, but acknowledged that “comfort and safety led him to living a ‘very dull life’, not to mention being at risk of isolation and depression” (p. 32). Madriaga advised against segregating students with autism further when accommodating their sensory hypersensitivities because it will perpetuate their isolation.

In addition to adjusting to new physical and academic environments, students with AS or HFA must learn to navigate the complex social world of college. Essayists in Prince-Hughes (2002) wrote of the challenges they faced socially while attending college. Susan described her avoidance of social situations because she was unsure of how to interact with others at these events, and was usually ignored by everyone there, leaving her depressed. O’Neal wrote that he had many more social failures than successes, and memories of his time as an undergraduate often involved spending Friday and Saturday evenings alone with nothing to do. Garry wrote of his attempts to make friends while attending college:

No matter how I tried I could not master the ability to make friends. I used to go for long walks and talk to myself as a means of self-talk and categorize my difficulties in making friends to the three strikes and you’re out scenario – I will best describe them as: 1. I’d say “Hello” – 2. Try to establish a conversation. – 3. I’d be avoided next encounter. I used to phone home quite a lot and my parents, especially my mother, was aware that I was very anxious and quite depressed (p. 2).

Willey (1999) wrote of her transition from successful high school student to struggling college freshman:

I was aware that college would bring many changes in my life. I knew the geographics and academics and amount of responsibilities and kinds of challenges would be different,

but I never gave thought to how different the social life would be. I had no way of knowing that (Asperger's Syndrome) left me without an intrinsic awareness of what it means to make and keep friends, to fit in and mold, to work cooperatively and effectively with others (p. 51).

She continued:

Without friendships, my version of friendships that is, I had very little support. Without peers to show me how to fit in and how to make the most of what I had, I could not stay connected. I foundered (p. 60).

College students with AS or HFA have found different ways of coping with their social struggles. Jim (Prince-Hughes, 2002) turned to the internet to find camaraderie and people similar to him, and Grandin (1986) found solace in her area of interest. Garry (Prince-Hughes, 2002) described his experience with an AS support group:

I now help run an Adult Support Group . . . We have many varied interests and are relaxed in each other's company and some of the members of the group are actually gaining confidence and suggesting outings and contacting one another by e-mail or phone (p. 4).

Participants in Muller, Schuler, & Yates (2008) qualitative study of the perspectives of adults with AS and other high-functioning autism spectrum disorders (ASD) regarding social challenges and supports were asked what types of externally implemented social supports they recommended. Participants suggested supports that included joint focus, shared interest, structured, and facilitated social activities. "The majority of participants also stressed the importance of membership within ASD-related groups, since these groups not only provided a joint focus, but also enabled participants to meet others like themselves" (p. 181-182). The

majority of participants reported that one-to-one conversations were their favorite means for socializing. “Most participants also noted that small groups – particularly in academic settings – could serve as an effective means of enabling positive social interaction. In contrast, participants often described feeling lost in big classrooms and on large college campuses” (p. 182). “A number of participants described how small groups served as natural ‘laboratories’ for learning about and mastering group dynamics, with several noting the importance of study groups and discussion groups” (p. 182). “Several stressed that creating intentional groups within an academic context would help to include the people who are not ordinarily included” (p. 183). Participants agreed that it was usually necessary for someone else to organize and maintain any group. Muller, Schuler, & Yates found that participants also valued opportunities to learn from more socially competent peers, direct instruction in social interaction, and alternative communication supports. Many participants utilized self-initiated supports that included creative outlets, physical or outdoor activity, spirituality, mediating objects, and time spent in solitude. The majority of participants emphasized the importance of attitudinal supports from others, including patience and caring, tolerance of differences, and willingness to initiate social interactions.

Willey (1999) offered advice for people with AS who are attending college:

Ask your counselor if the university has, or could establish, a friendship group for people with AS and related syndromes (p. 132).

She continued:

Everyone with Asperger’s Syndrome realizes it can be very difficult to establish close friendships. However, college life affords unique opportunities to make a variety of casual friendships all of which can serve to make the college experience more pleasant

and successful. An empathetic college will provide many opportunities for students to meet one another by promoting special interest groups across campus. Ask your guidance counselor to help you find a group made up of people who share your interests or hobbies and then do what you can to make a friend or two from among that group (p. 133).

Summary

Literature reviewed revealed the benefits of belonging to support groups in general settings for people diagnosed with AS or HFA. The benefits of group membership for members of other marginalized populations were also discovered. Experiences of people with autism were researched, and it was discovered that people with autism are more likely to suffer from Depression, Anxiety, and bullying. Narratives of People with Autism and AS revealed the challenges of living with the disorder, as well as the challenges and lessons learned while attending college. Studies and narratives of students with AS or HFA revealed struggles with transitions, sensory sensitivities, making friends, and navigating college life. The current study seeks to phenomenologically study the formation of a student organization for people with Asperger's Syndrome or High Functioning Autism, and to gain the perspectives of adults with Asperger's Syndrome or High Functioning Autism who have been to college.

CHAPTER III

Methodology

The original focus of the research was to phenomenologically study the experiences of college students with Asperger's Syndrome or High Functioning Autism as they established a student organization for those with the disorders. However, no students elected to participate. The focus of the study was then shifted in order to gain insight from adults with AS or HFA who had attend college. Qualitative interviews were conducted to obtain the opinions of these individuals regarding student organizations.

Phenomenological Study of Registered Student Organization for Students with AS or HFA

Design, research site and participants.

The original design of the project was to witness the formation of a registered student organization (RSO) for students with AS or HFA on the campus of a mid-sized public university located in a rural setting in the Midwestern United States. A phenomenological method of research was selected for use during interviews with individual participants, with the intent to gain their perspectives as well as the experiences of the group as a whole as the RSO formed. Mertens (2010) stated that phenomenological research emphasizes the individual's personal experience and perceptions and seeks to find what an experience means to the individual. Phenomenological research seeks to "understand and describe an event from the point of view of the participant" (p. 169).

Current enrollment at the university where this project was developed is approximately 11,500 students, with the vast majority enrolled full time and living on or near campus. 72% of courses offered at the institution contain fewer than 30 students. Ten students were identified as potential RSO participants by the student disability services department on the campus of the

research site. Each of these ten students had previously self-identified as having received a diagnosis of AS or HFA, and received services at the campus disability services department.

A staff member of the student disability services department presented these students with an invitation (Appendix A) to participate in the study during their regular individual meetings. A notice informing the campus population of the study, including the group function and meeting time and locations was also posted in the electronic university newsletter (Appendix B), and a press release containing this information was sent to the campus newspaper (however, the student newspaper did not publish anything in relation to the study). The Speech Clinic at the research site was asked if they had clients who would be interested in participating. No participants were found via any of these methods.

Establishment of an RSO and meeting formats.

In order to commence the process of forming an RSO at the research site, student participants would have had to have accessed an application for formal establishment of the student organization at the institution's web site. The prospective RSO must state the purpose of the organization, list of a minimum of 10 current members, and the name and contact information for a faculty or staff advisor as well as student officers on the application. The application must be printed and signed by the advisor and student officers and submitted to the office of student programs, along with a copy of the organization's constitution developed by the organization's members. Once established, the RSO must register annually.

The proposed RSO for students with AS or HFA was to have been advised by a graduate student who was studying communication disorders at the study site, and who would have facilitated discussion and ensured that no one member of the group monopolized discussion. Meetings would have had a social focus with a casual atmosphere including a flexible but clearly

stated agenda consisting of member introductions, information from the advisor, followed by an activity or discussion of a topic selected in advance by the group. Meetings would have taken place on campus in a non-clinical setting. The group would have been offered a choice of meeting weekly or every other week. The members of the group would have decided the group's name and what, if any, additional activities would have been pursued.

Data observation and collection.

Data could not be collected from this original design, given that no students with AS or HFA opted to participate. The researcher planned to observe as a passive participant (physically present, but not interacting with the participants) during each meeting of the emerging student organization. Group activities and discussions were to have been recorded and transcribed, noting such nonverbal behaviors as facial reactions or gestures. Participant interactions, relationship development, and apparent comfort levels (physical and social) were to have been observed and noted. The researcher also planned to monitor attendance and attrition. At the end of the study, the researcher planned to convene a focus group to ascertain member perceptions regarding the formation of the group.

Qualitative Interviews of Adults with AS or HFA who Attended College

In an attempt to pursue perspectives as to why the formation of an RSO for students with AS or HFA was not successful, the focus of the research was adapted to include qualitative interviews with former college students identified as having autism. Participants were asked to reflect on their prior college experience and the prospect of belonging to an RSO in order to assist with future research in this area. The effect that maturity may have on persons with Asperger's Syndrome or High Functioning Autism's willingness to become involved in organizations was

also explored. For the purpose of this study, opinions of participants who had left college fifteen years prior to participating in the qualitative interview would be evaluated.

Design, research site and participants.

Mertens (2010) described a qualitative researcher as someone who attempts to understand or interpret phenomena in terms of the meaning people bring to them. According to Mertens (2010), qualitative research is appropriate when the focus of research emphasizes individual outcomes or diversity and unique qualities exhibited by individuals, and is practical when a study is based on humanistic values and personal contact is desired. This study sought the opinions of individuals diagnosed with AS or HFA, and it was recognized that each individual would have unique feelings, perspectives, and contributions, each of which would be valuable to the research. Therefore, qualitative interviews were conducted in order to obtain the most extensive data possible.

Qualitative interviews of adults with AS or HFA who had attended college were conducted at a location of the participants' choice, in order to maximize their comfort level. Two interviews took place at the home of the participants, one took place at the participant's office, and one took place at a private room of a restaurant.

Adults who once attended college were invited to participate in qualitative interviews through acquaintances of the researcher. Four adults consented to participate. Attempts were also made to obtain interview participants via the snowball effect (asking participants if they knew of anyone else who would like to participate); however, no participants were found via this method.

Carlos, a 27-year-old male, attended a community college close to his home, starting at the age of 18. He received an Associate's Degree after three years of study. Carlos lived with his parents while attending college, and reported that he had 3 or 4 friends while he attended college.

Carlos did not know he had AS while he was enrolled in college, and did not receive services from the campus's student disability services department. He reported that he was aware that smaller class sizes worked better for him, and that he worked with his advisor to be sure he was enrolled in classes that were smaller in size. Carlos described college as "being alone in a sea of people," and stated that he felt very anxious, isolated, and unprepared for the social and emotional rigors of college.

Don, a 59-year-old male, enrolled in a small private college about 50 miles from his home. After one year, he changed his major and transferred to a different small college away from home that specialized in this major. He received a master's degree from a third college, and married during this time. Don reports that he is "a loner" and that he "probably only had a couple" of friends at that time in his life. Don did not know he had AS while he was enrolled in college, and did not receive services from the campus's student disability services department. He indicated that, while he was excited to move out of his parents' home and live independently, change and transition were difficult for him when he was in college. His sensory defensiveness left him feeling "emotionally guarded" while he was attending college. Don is currently employed on a university campus.

Frank, a 31-year-old male, attended a mid-sized public university located approximately 200 miles from his home. He lived on campus and attended for 12 years, receiving 3 Bachelor's Degrees. He belonged to a fraternity while in college (initially joining to enhance his social skills), and lived in a single room in his fraternity house for a time. Frank reported that he had about 2,000 friends while he was in college, but these were primarily friends in social media, and he considered 5 or 10 of them to be close friends. Frank had been diagnosed with AS prior to his enrollment in college, was registered at his university's student disability services department,

and received appropriate accommodations for his classes. Frank reports that, while he was happy to be on his own, he was initially apprehensive about college because he didn't know what to expect, and that, "maybe the first month or two was kind of difficult for me emotionally but once I get the hang of things I'm able to maybe take everything in stride."

Peggy, a 27-year-old female, was diagnosed with HFA as a child. For 6 years, she attended a community college near her home, starting at the age of 19, and graduated with a Liberal Studies degree. Her parents are divorced, and she alternated living with each of her parents while in college. She was registered with the student disability services department on her campus, receiving extended time for exams and tutoring services. Peggy belonged to the TRiO Student Support Services group on her campus and enjoyed the experience, particularly group activities. She was also a member of the school choir. Peggy stated that she had several acquaintances while in college, having met them through TRiO and the choir. Peggy also reported that she was bullied by a group of students she met in the cafeteria at the college, and that the experience affects her emotionally to this day.

Data collection.

Prior to each interview, participants were informed of the purpose of the study and completed an informed consent form (Appendix D). All participants were assigned pseudonyms, which were used throughout the study. Data was collected via 22 interview questions (Appendix C). The questions were a mixture of demographic inquiries and open-ended items. It was necessary that questions be direct and short in length, as the nature of the disorder involves difficulties in processing information and communicating thoughts.

Six questions (Appendix C) were utilized to explore and identify the potential needs of college students with AS or HFA:

- Did you have friends when in college?
- If yes, approximately how many?
- Were those friends also in school?
- Describe those first few weeks of college
- Describe your college experience overall emotionally
- Describe your college experience overall academically

To obtain the insights of people with AS or HFA who have been to college and to develop an understanding of their feelings regarding group membership, seven sub-questions (Appendix C) were utilized:

- Thinking about who you were when in college, if there was the opportunity, would you have joined a group for students with autism?
- Why or why not?
- What do you think would be the benefit of such a group?
- What do you think would be the disadvantage of such a group?
- What challenges could you foresee if a group was trying to be established on a campus?
- Do you have any suggestions to help a group like this be successful?
- Thinking about who you were when in college, if there was the opportunity, would you have joined a group for students with the same areas of interest as you?

To determine if people with Asperger's Syndrome or High Functioning Autism change their opinions regarding involvement in organizations as they mature, two questions were utilized:

- Would you join a group for people with autism in your community now?

- Why or why not?

Data analysis.

All qualitative interviews were audio recorded and transcribed by the researcher.

Transcriptions text was then redacted to remove any references the interviewers made that could potentially allow them to be identified. Filler words such as “um” and “ah” were eliminated.

Data were reviewed and categorized by several themes that emerged. These themes were used to understand the perceptions of adults who had attended college in regards to student organizations for students with AS or HFA.

CHAPTER IV

Results

This chapter discusses efforts to develop an RSO for students with AS or HFA, as well as opinions of adults with AS or HFA who have been to college regarding student organizations for their population.

Research Question #1: What are the perceptions of students with Asperger's Syndrome or High Functioning Autism when invited to organize a registered student organization?

Question one sought to collect the reactions and initial feedback of college students with AS or HFA when invited to organize an RSO in order to understand their initial perceptions regarding group involvement prior to the actual experience. However, reactions and feedback were not able to be recorded, as no students elected to join the group or participate in the study.

Research Question #2: What challenges and/or issues emerge as the registered student organization is being formed?

Question two sought to gain an understanding of the experience of the formation of an RSO for this student population through phenomenological research. However, as noted under question one, none of the students elected to join the group or participate in the study. As stated in Chapter 3, a staff member in the student disability services department presented ten students with invitations (Appendix A) to participate in the study. None of these students arrived at the initial group meeting. One former student of the campus research site who had heard about the study arrived at the initial meeting and indicated interest in participating in the group. However, he was not qualified for the study because he no longer attended the university. Attempts were made to interview the students who were invited to participate. However, the student disability

services staff member who initially presented the students with invitations declined this option, citing concern that interviews may cause the students discomfort.

Research questions three and four were developed to investigate the opinions and perceptions of post-graduate participants self-identified as having AS or HFA regarding the difficulty forming an RSO for students with AS or HFA. The four participants (three men and one woman) agreed to share their thoughts regarding student groups for students with AS or HFA. Through their interviews, trends emerged and information was gathered for the last two research questions.

Research Question #3: What are the perceptions of adults with Asperger’s Syndrome or High Functioning Autism who have been to college regarding the establishment of student organizations for students with Autism?

This research question sought to obtain the insights of adults with AS or HFA who have been to college, in order to develop an understanding of their feelings regarding group membership. Seven sub-questions (Appendix C) were utilized to answer the research question.

Participants’ thoughts regarding belonging to an RSO for students with AS or HFA.

Two of the four post-graduate participants indicated that they would have joined an RSO for students with AS or HFA, while the other two indicated that they would not have participated in a group of this nature. One participant also indicated that he would have joined an organization for students with disabilities unspecified.

Participants who would have joined an RSO for students with AS or HFA.

Peggy enthusiastically stated that she would have joined an RSO for students with AS or HFA. Frank indicated that he would have joined an organization of this nature as well, but probably would have waited until his sophomore year, saying, “maybe not right away cause I

want to get my feet on so I can have different experience(s) so maybe my second year I probably would have joined.” Both Peggy and Frank indicated an eagerness to meet others with similar challenges. Peggy indicated an interest in, as well as a history of, joining groups both for people in her population and pertaining to her interests, and stated that if she had been able to join a group of this nature while she was in college, “it would have helped me because I like to know other people with my sorts of difficulties.” Frank indicated that he would also have joined an organization for students with disabilities unspecified and indicated a desire to interact with students with diverse disabilities, “I could maybe meet other people who have, in addition to being in college . . . have like different kinds of disabilities or exceptionalities.”

Participants who would not have joined an RSO for students with AS or HFA.

Carlos and Don stated that they would not have joined an RSO for students with AS or HFA. Both indicated that participating in groups made them feel uncomfortable. When discussing his reasons for not wanting to join a group of this nature, Carlos said, “Things like group and extracurricular activities were something I just did not like to do because I just I didn’t want to be with people – I just didn’t want to do that.” When discussing groups in general, Carlos said, “I really don’t like the group setting . . . when you get a group involved, it’s just too much to handle.”

When asked why he would not want to join an RSO for students with AS or HFA, Don responded, “Because of the word ‘group’.” Don described the challenges he faces when participating in a group setting:

I think the whole idea of forming a group to help people who have Asperger’s, is kind of like . . . inviting anorexics to a pot-luck dinner . . . it’s the exact opposite thing you would want to do to try to help them. Not that you can generalize because there is a huge

spectrum of differences – in the intensity, how far in the autism spectrum an Asperger person is . . . But we do seem to share issues with socialization and we need help with the socialization. We interact awkwardly in social settings. And so, the problem with the group is going to be – can you get these people in a group and have them actually feel like they're comfortable in that setting and want to open up in that setting . . . I just think group is probably not the area where they're gonna feel comfortable enough to let their guard down. We have all these issues with the eye contact. I have to work at eye contact in a group – it's not as hard in one-on-one, but in a group I'm always wanting to gaze off somewhere else. I just think the group setting is probably the thing that...you're asking the Asperger to overcome one of their major hurdles to accept themselves. It's like asking a one-legged man to climb a ladder to get to the next floor.

Carlos and Don voiced concerns that membership in an RSO for students with AS or HFA would mandate disclosure and potential stigmatization. Carlos said, "There would be like a stigma to it, it's like 'Well you're broken why don't you sit down with all these other broken people and talk about how you're broken.' And . . . I would probably just not want to do that." Don indicated that he does not want to be labeled and does not wish to disclose his diagnosis because it would leave him vulnerable to teasing or that people may jump to conclusions about him.

Don was not opposed to receiving support in other ways, and suggested other forms of support. Don said:

I think that there are things that a university could do to help people with Asperger's integrate into the academic situation . . . I would have gone to talk to someone who was knowledgeable about it (Asperger's Syndrome) . . . I've been thinking about what would

have helped me integrate and have been better in school or more comfortable if I had a mentor who understood it that I could go talk to and help me navigate my way through. Even to the extent of like, vocational counseling.

Participants' perception of benefits of belonging to an RSO for students with AS or HFA.

Adults with AS or HFA who had attended college were asked about their perceptions and experiences regarding student organizations for their population. Participants shared their thoughts regarding benefits of participation in a group of this nature.

The opportunity to meet students who are similar to themselves.

Three of the four participants in the qualitative interviews indicated that they felt that members of an RSO for students with AS or HFA would benefit by getting to know other students with similar challenges. Three of the participants expressed the desire to meet someone else who has autism. Carlos indicated a desire to meet another person with AS or Autism who is “higher-functioning like me.” Peggy stated that if she had been able to join an RSO for students with AS or HFA while she was in college, “it would have helped me because I like to know other people with my sorts of difficulties.” Frank indicated that the reason he would join an RSO of this nature was to enable him to interact with students with diverse disabilities, “I could maybe meet other people who have, in addition to being in college . . . have like different kinds of disabilities or exceptionalities.”

The opportunity to share and receive practical information.

Participants indicated that a foreseeable benefit to belonging to an RSO for students in their population would be the sharing and receiving of practical information. Three of the four participants interpreted the purpose of the student organization as a means of concrete support

and assistance. Peggy stated that belonging to such a group, “would basically help if they (the group members) learn . . . what was easy, what was difficult.” When discussing the benefits of belonging to such an organization, Frank saw a practical reward for getting to know other students in a similar situation, “[we can] make sure we are receiving the services that we need in the classroom as well as socially and in the community if possible.”

Therapeutic and emotional benefits.

Two of the participants felt there could be therapeutic benefits to belonging to an RSO for students with AS or HFA. Despite having no interest in joining a group of this nature, Carlos indicated that he saw a potential benefit for others who would belong to a group. Carlos said:

You’re interacting with people like yourself . . . you can get some insights and realize . . . you’re not the only one going through this, there are other people in your exact situation, you know, ‘Hey – you’re going to college, they’re going to college, and they’re dealing with the same problems you’re having.’ So, it would kind of be a relief, ‘I’m not the only one carrying this burden.’ You know, there’s others. So, that would be comforting.

Carlos also considered another positive impact that group membership might have on its members, “it would give them confidence – they CAN interact with other people.” While discussing the benefits of belonging to an RSO for students with AS or HFA, Peggy stated that it would be beneficial to learn “about our emotions and stuff” from other members.

Public awareness.

While Don saw no benefit to belonging to a group for students with autism, he did feel that there would be a benefit to the campus and to group members indirectly, “I think the benefit of a group like that would probably be awareness of people that are not Aspies that there are people on campus that are like that.”

Participants' thoughts regarding challenges that an RSO for students with AS or HFA may face.

Adults with Asperger's Syndrome or High Functioning Autism who had attended college were asked about their perceptions and experiences regarding student organizations for their population. Participants shared their thoughts regarding challenges that a group of this nature would face.

Low attendance.

As evident by the unwillingness of any of the ten potential participants to participate in the phenomenological study of an RSO for students with AS or HFA, a major challenge for a group of this nature is attendance. Concerns regarding member attendance were also raised by participants in the qualitative interviews of adults with AS or HFA who had attended college. When asked about potential challenges a group of this nature might face, Carlos said, "Well mainly it would be the attendance. I really think that would be the foremost issue. It would just be hard to get people to go to it." Don stated that groups are difficult for people with autism and said, "I just don't feel like, forming groups, or having an Asperger's RSO or something like that...we don't like basically that kind of socialization."

Negative emotional impact.

Two of the participants expressed concerns regarding potential negative emotional impact. Peggy voiced concerns about group members "clashing" or not getting along. Carlos voiced concerns about potential emotional consequences of participation in a group of this nature:

It may bring some things to the surface that people may not want to talk about. I could see . . . a lot of pressure being put on these people . . . to get them to come out of their

comfort zone. For some people not like myself it could go *really badly*; it could probably do some damage.

Carlos added:

It's like 'Well you're broken why don't you sit down with all these other broken people and talk about how you're broken.' And... I don't know I just I would probably just not want to do that.

Stigmatization.

As stated earlier, three of the four participants voiced concerns that membership in an RSO for students with AS or HFA would mandate disclosure and potential stigmatization. When asked about potential disadvantages of belonging to an RSO for students with AS or HFA, Frank said, "I don't see any real disadvantages except for maybe people knowing that you have a disability." Carlos also stated he felt there would be a stigma attached to belonging to a group of this nature. Don also voiced concerns about stigmatization:

You're gonna end up with a group of people that are labeled by other people and once you label 'em, people could point fingers and make fun. And about the last thing in the world someone who . . . already struggles with social issues, is to be labeled and pointed out, 'Oh look at the Aspies – there goes the nerds.' I don't tell very many people I am (autistic), because I don't want to be labeled. And people don't always understand as much as they think they do about a situation, and then you get labeled and they jump to conclusions.

Don also voiced concerns about the legality of disclosure, "I've even wondered if HIPAA rules will allow the identification of people with Asperger's in a group. There have to be some legal issues with a university identifying these people publicly."

Differing opinions regarding purpose, function, and structure of group.

As with any group of individuals, there are differing opinions regarding what the purpose, function, and structure of an organization should be. Emotional and social needs of group members differ to varying extremes, and each member has his or her own thoughts regarding the type and frequency of group meetings and activities. Participants in the study had varied recommendations for the success of an RSO for students with AS or HFA. When offering suggestions for the success of a student organization of this nature, Peggy stated she would like to see a group participate in social activities, and for meetings to be structured, “I think maybe someone leading the group and having more of a discussion topic . . . (and) like, go on field trips and go out to lunch and stuff.” Carlos felt the opposite approach would be more effective and indicated that he would like to see group meetings that did not follow an agenda or contain structured activities, Carlos said:

Just make it very informal just say you know, it’s like, ‘hey there’s gonna be people around like yourself, and we’re just gonna hang out. And that’s all it’s gonna be.’ . . . So there’s no like, coordinated activities or anything like that. That’s one thing I don’t like. I don’t like structured activities like that . . . It doesn’t work for people like that. Like myself.

Peggy indicated that an RSO for students with AS or HFA should include discussion topics related to emotional issues, “It would basically help if they (the group members) learn more about each other – what was easy, what was difficult. And about our emotions and stuff.” Carlos, however, voiced concerns that members may feel pressured to come out of their comfort zones and be forced to discuss issues they do not wish to confront.

Frank indicated that the main function of an RSO for students with AS or HFA would be members' ability to share and receive practical information, in order to ensure they are receiving the services they need. While Don saw no benefit to belonging to a group of this nature, he discussed alternatives that involved practical assistance, implying that he believed the function of the group was to assist student with AS or HFA in practical and therapeutic ways. Peggy viewed the primary function of a group of this nature was to provide opportunities for socialization, and Carlos indicated through his responses that he believed the primary function of a group of this nature would be group counseling.

Participants' suggestions to assist in the success of an RSO for students with AS or HFA.

Adults with Asperger's Syndrome or High Functioning Autism who had attended college were asked for their recommendations for the success of an RSO for students in their population. Participants in the study had varied recommendations for the success of group of this kind. Frank was unable to offer suggestions during the interview for the success of a group of this nature, and later e-mailed recommendations to the researcher based on information he stated he found on the Internet. It can be inferred that he agreed with these recommendations.

Activities that promote socialization.

Participants had varied recommendations for the success of an RSO for students with AS or HFA. While participants made suggestions that emphasized socialization, each had different ideas regarding fostering it. When offering suggestions for a student organization of this nature to be successful, Peggy stated she would like to see a group participate in social activities, "like, go on field trips and go out to lunch and stuff." Frank offered suggestions that included activities that promote "people working together while having some fun," such as a spa day, beach party,

or Chinese auction. Carlos suggested that meetings encourage small group or individual interaction in order to foster socialization:

If you just got like a couple people together you know . . . I don't know, like if say there was 4 – pair them off. You know, make it really small. Don't make it seem so like it's a big deal. Like, this is like a BIG GROUP. Just kind of considerate it as like a small, intimate gathering. And don't do everything like in a group . . . break it off, you know? Like a couple people might become really good friends.

Meeting structure.

When discussing her thoughts regarding what an RSO for students with AS or HFA would need to be successful, Peggy suggested, “I think maybe someone leading the group and having more of a discussion topic.” Frank e-mailed a recommendation to the researcher that suggested engaging the group in structured “activities to promote talking, reminiscing and learning.” Carlos, however, expressed the opposite and indicated that he would like to see group meetings that did not follow an agenda or contain structured activities. Carlos said:

Just make it very informal just say you know, it's like, ‘hey there's gonna be people around like yourself, and we're just gonna hang out. And that's all it's gonna be.’ It's like, ‘well what's gonna happen?’ ‘I don't know you're just gonna hang out that's it.’ So there's no like, coordinated activities or anything like that. That's one thing I don't like. I don't like structured activities like that. It's like, ‘hey we're gonna all do this!’ and ‘let's all get together and do this!’ That doesn't work for those people. It doesn't work for people like that. Like myself. It doesn't work.

Participants' thoughts regarding belonging to other types of groups.

Participants were asked if they would have joined an RSO that was devoted to an area of special interest to them while they attended college. Peggy and Frank both indicated that they had participated in groups dedicated to areas of interest to them while they were in college and enjoyed their time with the groups. Don reaffirmed that he would not have joined any type of group while he was in college, but indicated that he would have been interested in meeting individuals with interests similar to his.

Don said:

If I knew somebody on the campus that that was also their interest, I would probably look at them as an object – a person whom I could form a friendship with. ‘Cause my friendships do tend to focus on shared interests. And so, I in the one-on-one aspect, I might end up with a buddy who has my - my shared interest. But even if that buddy belonged to a group, I wouldn’t join the group that he belonged to.

When asked if he would have joined a group relative to his special interests while he was in college, Carlos was the only participant who felt differently about these groups as opposed to a group for students with AS or HFA. Carlos said, “Yeah, I would. Yeah. But ‘cause it’d be such a niche interest that I’d definitely want to find other people. Probably.”

Research Question #4: Do age and maturity affect a person with Asperger’s Syndrome or High Functioning Autism’s opinion regarding the joining of a group?

This final research question was designed to see if people with Asperger’s Syndrome or High Functioning Autism change their opinions regarding involvement in organizations as they mature. Two questions (Appendix C) were utilized to answer the research question. There was only one participant who met the criterion for this portion of the research; therefore, it is difficult

to draw any conclusions as to whether age or maturity could affect the opinion of a person with AS or HFA in regards to their decision to join a group.

Don, the sole qualitative interview participant who qualified for this portion of the research, indicated that he would not join a group of any kind at the present time, including a support group for his population or groups that focused on his areas of interest. This indicated that in his case, Don's opinions regarding group involvement were not influenced by the passage of time. Don had the same reasons for not wanting to join a group now as he did while he was in college:

I don't join groups. That's the thing – I have a lot of activities that I enjoy and it's funny because I . . . like anything that's mechanical and requires precision and things that I enjoy, but I never want to join a club that has to do with those things. I'm not a joiner. I'm not a joiner . . . I actually have . . . concrete instances of this in my life . . . one of my best friends is an international [activity] champion, and . . . they're always wanting me to go with them to their club meetings, and I'd almost rather get a beating than have to go and interface with all these other people. I feel like I – I feel so awkward. I'm in misery in those situations.

Additional Themes

Participant responses to the research questions elicited several themes that were not related to the initial research questions, yet offered relevant insight into their social perspectives and challenges. Themes that emerged included participants' desire to meet people who are similar to themselves, level of functioning potentially affecting participants' desire to belong to a group, challenges when transitioning into college, emotional concerns and bullying, participant

misconceptions regarding the purpose and function of the proposed RSO, and additional forms of support.

Participants' desire to meet people who are similar to themselves.

Three participants indicated that they desire individual connections and wish to meet people who are similar to him or her, whether it is someone with common challenges, or someone with common interests. Carlos said, "I want to find somebody who's more higher-functioning like me, who doesn't really struggle with a conversation. 'Cause I have not found one yet'." Peggy indicated that she likes to know other people who experience the same difficulties as she does. Frank stated that he wants to meet people with disabilities. Don indicated that he would form friendships with individuals who share his interests, but would not be interested in being involved in a group of people who share his interests.

Level of functioning potentially affecting participants' desire to belong to a group.

The researcher noted that two participants, Don and Carlos, did not display outward characteristics of autism upon first meeting them. Neither of them outwardly presented with common symptoms of autism that the two other participants, Frank and Peggy, struggled with: poor eye contact, repetitive motions, difficulties with spontaneous conversation, and clumsy mannerisms. It is interesting to note that Don and Carlos were vehemently opposed to belonging to a group and were very concerned about stigmatization, while Frank and Peggy were eager to join a group, and not as concerned about stigmatization.

Challenges when transitioning into college.

Participants discussed their transitions into college. Three of the four participants described difficulties with change and transition, sensory sensitivities, and anxiety. Frank described the first month or two of college as being "difficult for me emotionally," and described

feelings of anxiety, “I was kind of afraid . . . I sense apprehension because I didn’t know what to expect.” Don described his transition to college, “I would say I was a scared 18-year-old when I went to college . . . my resistance to change was huge.” Don also transferred to another school and attended a third college for graduate school. He described each transition as being difficult for him, “pretty much every school I ever went to . . . it was scary to make the change.” Carlos described his struggles as he transitioned into college:

When I started I was really nervous because I didn’t know what I was going to expect. It was completely different than anything else because it was college and I could never really see what it was like from afar. And so I was just nervous about how it was going to, like, would I have to work harder? . . . Would I have less free time? Would I basically just have to change my whole – the way I operate because of college? I probably tended to over analyze things, think of things too much. Stress out a lot...I felt really you know alone, and it wasn’t like high school, and high school doesn’t really prepare you for what you’re gonna go through in college because it’s just so different.

Emotional concerns and bullying.

Participants indicated that they experienced feelings of isolation, anxiety, and depression as well as bullying while they attended college. Two of the participants indicated that they suffer from comorbid mood disorders. Don described himself as “kind of a loner,” and stated that his sensory issues left him emotionally guarded and caused him anxiety, stating, “testing really frightened me.” Peggy reported being bullied while she attended college, and that it left her “wounded.” Carlos reported feelings of anxiety while he attended college, “I probably tended to over analyze things, think of things too much. Stress out a lot.” He described feelings of loneliness, isolation, and depression:

The thing about college is, it's like being alone in a sea of people. That's what college is, to sum it all up. If I could sum college up in one sentence, that's what it is. A lot of isolation. Time with your feelings. You realize, 'wow this is really dark.' It's like you're just sitting there, with yourself and realizing it's like, 'aw man, I don't like this.'

Participant misconceptions regarding the purpose and function of the proposed RSO.

In the qualitative interviews of adults with AS who had attended college, misconceptions regarding the purpose of the proposed RSO for students with AS or HFA became apparent. At the onset of the interview, the researcher verbally explained the purpose, function, and structure of the proposed RSO, and explained that members of the group would determine the format of group meetings as well as group activities. Despite these explanations, three of the four adult participants misperceived the purpose of the RSO as a means of support and assistance, as opposed to its intended opportunity for socialization. When discussing the potential benefits of belonging to an RSO for students with AS or HFA, Frank stated that he believed the primary benefit would be that members received the classroom, campus, and community services that they need. Carlos indicated his belief that there would be facilitated group discussion regarding autism, and did not understand that group members would choose the RSO's activities and format. Don felt there was no benefit whatsoever in belonging to a group of this nature, and discussed alternative methods for assistance, indicating that he felt the purpose of such a group is for assistance to the students who belong to it. Peggy was the sole participant who understood the purpose of the group as it was explained to her, and her answers focused on the social aspect of belonging to a group, while recognizing potential therapeutic benefits of membership.

Additional forms of support.

Participants were also asked about their collegiate experiences. Responses highlighted the need for support and services outside of the classroom. Carlos said, “I found that most of the teachers weren’t really any kind of help. I felt really alone.”

Social and emotional guidance.

Don stated he would have had a better collegiate experience if he had received guidance from someone who was familiar with Asperger’s Syndrome:

I’ve been thinking about what would have helped me integrate and have been better in school or more comfortable. If I had a mentor who understood it (Asperger’s Syndrome) that I could go talk to and help me navigate my way through.

Carlos described his struggle to find enjoyment in college:

I don’t really have a lot of positive experiences from college. It’s a lot like I . . . just like, go to class and then wait for the next class, and just a lot of waiting for the next class and it was so . . . I would just be there all day.

After she experienced a trauma, Peggy’s challenges with regulating her mood and controlling her impulses, combined with her misunderstanding of socially-appropriate behavior led to her receiving disciplinary action at her college. Peggy described the event:

. . . my first year I started I got in trouble because I was in a car wreck with my mom and my sister . . . Someone else like rammed into us. Then my dad came and he helped me out and stuff and I went to school. I was upset and scared and I saw this girl from my high school . . . and this other girl and she had some severe disabilities and she was in a wheelchair. And when I was upset from being in the car accident I felt traumatized and I

tapped the back of her wrist. And she went and told disability services that I assaulted her. And I was put on probation for a semester.

Peggy also reported being bullied by other students while she attended college. Once again, Peggy's challenges with regulating her mood and controlling her impulses, combined with her misunderstanding of socially-appropriate behavior worsened the situation. Peggy described the events:

I was bullied and it was really bad. I just met them randomly at lunch in the cafeteria. They bullied me. I got upset and I lashed back at them. And I made some texts that were violent towards them. And it was on Facebook and on the phone. And it led to – it left me - wounded even after college because . . . I had seen some of the same people that had bullied me at (college) and I had the same troubles I had lashed back at them. I talked by making the threatening comments to them on the phone and on Facebook. And it led to trouble with the police . . . They told me to stay away from them and they told them to stay away from me.

Additional academic guidance.

Participants discussed situations where they struggled academically and either benefitted, or would have benefitted, by working with an academic advisor or instructor who was familiar with their challenges. Carlos described academic struggles related to his AS that could not have been remedied by typical classroom supports and disrupted his ability to focus, “some of the classes – I didn't understand why I had to take some of these classes. I didn't get the point.”

Carlos had not been diagnosed with AS at the time he attended college, and did not receive services from the student disability services department on his campus. Carlos knew that

he was more successful in classes with fewer students, and advocated for himself when working with his academic advisor. Carlos said:

I had an advisor. I spoke to them about what classes would work best for me because of my situation . . . I worked better in smaller classes . . . so they just pointed me in the right direction of what classes would work good for me, in my situation.

Peggy reported that her academic difficulties led to her membership in TRiO Student Support Services, which offered her social opportunities that she really enjoyed. Peggy said:

. . . writing papers was difficult for me. So my teacher recommended me to do TRiO. And I signed up for it. And we had like, all these banquets. And the places we travelled to – one of the places we travelled to was the Arch in St. Louis. And we got to go up in that little tram.

While Don did not struggle academically, he stated that he would have benefitted from academic and vocational guidance from someone who was familiar with Asperger's Syndrome. Don said:

If I had a mentor who understood it (Asperger's Syndrome) that I could go talk to and help me navigate my way through. Even to the extent of like, vocational counseling - what track should I have chosen. There might have been some better tracks for me to have chosen academically and career-wise than what I chose.

Summary

This chapter presented the perceptions, insights, and opinions of adults with Asperger's Syndrome or High Functioning Autism who had attended college regarding student organizations for college students in their population. Several themes emerged. As with any population, there were mixed opinions regarding the joining of a group. However, the reasons

participants gave for wanting and not wanting to join groups were significant: Two participants felt extremely uncomfortable in group settings and indicated that sensory sensitivities were a factor; three of the four participants perceived the purpose and function of the group to be different than what was explained by the researcher; three of the four participants were concerned about disclosure and stigmatization; and concerns regarding potential negative emotional impact were raised. Participants also recognized potential benefits to belonging to an RSO for students with AS or HFA: it would be nice to know other people with similar challenges; members could be certain they were receiving all available campus services; members may gain self-confidence; and activities could be fun.

Attempts were made to form an RSO on a mid-sized university campus so that knowledge could be obtained from that experience, but none of the students who were invited were interested in participating in the group.

CHAPTER V

Discussion, Conclusions, and Recommendations

The present study sought to observe the formation of a student group for college students with Asperger's Syndrome or High Functioning Autism using phenomenological methods and to obtain the insights of adults with the disorders who had attended college through qualitative interviews. Autism is a complex disorder with a wide range of symptoms and functionality, and, as one participant pointed out, there is a broad spectrum of differences but persons with autism are frequently generalized. Despite participants' differences with each other, several themes emerged, which will be discussed in this chapter. Implications for student affairs practitioners and recommendations for further research will also be discussed.

Discussion

Phenomenological study of an RSO for students with AS or HFA.

Students who self-identified as having received a diagnosis of Asperger's Syndrome or High Functioning Autism were invited to participate in the study by a staff member of the student disability services department at the research site. A notice was also posted in the university newsletter (Appendix B). None of the students who were invited to participate in this portion of the research elected to participate. Additionally, none of the students who were invited consented to an interview; therefore it was not possible to gain knowledge firsthand as to why they were not interested in participating. The lack of student enthusiasm for the study was disappointing, but not surprising, given some of the characteristics of AS and HFA, findings of previous relevant research regarding autism, and statements made by participants in the qualitative interview portion of the study.

Characteristics of Asperger's Syndrome and High Functioning Autism.

Several characteristics of AS and HFA can influence an affected person's willingness or ability to participate in an RSO for their population.

Deficits in executive function.

According to G. J. Richard (personal communication, November 30, 2011), a pattern of deficits in executive functioning is present for individuals with Asperger's Syndrome. These deficits affect a person's working memory, judgment, and planning ability. Bolick (2004) included "inefficient organization and productivity," when describing possible practical characteristics of Asperger's Syndrome. Due to deficits in working memory, planning ability, and organizational skills, persons with AS struggle to remember appointments or other activities that are not a part of their usual daily routine. When scheduling interviews for the qualitative portion of this study, three of the four participants were present for the interview only because a family member scheduled the time and location with the researcher, frequently reminded the interviewee of the interview, and/or actually brought the interviewee to the meeting. One qualitative interview participant forgot the interview appointment twice and had to be rescheduled. A fifth potential qualitative interview candidate indicated an interest in participating but failed to arrive for the interview, explaining later that he forgot about it. Students who are living independently do not have a person to remind or insist that they go to group meetings. It is possible that some potential participants at the research site with AS may have been interested in participating in the study, but did not remember to attend the meeting and did not have someone to remind them to attend.

According to Attwood (1998), persons with Autism struggle with Theory of Mind, which is the understanding that other individuals have beliefs and desires that differ from their own, and

have difficulty conceptualizing and appreciating the thoughts of another person. The three participants who were diagnosed with AS formed immediate and inaccurate impressions of the function and purpose of the proposed RSO for students with AS or HFA, and were unable to comprehend the function and purpose as it was described to them by the researcher. This is consistent with Attwood's description of Theory of Mind deficits in persons with Asperger's Syndrome.

Challenges with socialization.

Prince-Hughes (2002) wrote of the difficulty that people with Autism have with organizing groups, stating that the symptoms of autism (such as difficulty coping in social situations, aversion to direct eye contact, and difficulty quickly responding conversationally), prevent many people with autism from finding each other and organizing sustainable real-time meetings. Muller, Schuler, & Yates, (2008) qualitatively studied the perspectives of adults with AS and other HFA spectrum disorders regarding social challenges and supports, and found that participants did not understand how to initiate social interactions and attempting to do so was a source of tremendous anxiety. In qualitative interviews in this study of adults who had attended college, two of the four adults interviewed indicated that they are very uncomfortable in group settings of any kind, due in part to challenges with socialization. Carlos discussed his reasons for not wanting to join a group, "You know, I really don't like the group setting . . . when you get a group involved; it's just too much to handle." When discussing his social anxieties, Don emphasized that presenting autistic students with the very thing they are challenged with (a social setting) in order to assist them is counterintuitive. It is possible that potential participants who experienced challenges socially were apprehensive about joining the student organization because they believed they would face the same challenges in this situation as well.

Sensory sensitivities.

Prince-Hughes (2002) wrote that many students find the university a formidable mixture of overwhelming sights and sounds. As Madriaga (2010) discovered, students with AS or HFA who experience sensory processing issues were unable to enter typically social university spaces without triggering anxieties or sensory hypersensitivities. While several of the participants in Madriaga's study desired social interaction, they were isolated from their peers because of their sensory sensitivities. In qualitative interviews in this study of adults who had attended college, two of the four adults interviewed indicated that they are very uncomfortable in group settings of any kind, partly due to their sensory hypersensitivities. Don stated that his sensory defensiveness left him feeling "emotionally guarded" while he was attending college and Carlos expressed his discomfort among crowds of people. It is plausible that potential participants were reluctant to attend due to sensory sensitivities to the location of the meeting.

Uncertainty about what would take place during the meeting caused anxiety among potential participants.

According to Bolick (2004), persons with AS have a preference for predictability, accompanied by problems in regulating anxiety or mood. Jantz (2011) found that adults with AS prefer support group meetings that are structured, with group rules clearly explained. Printed invitations (Appendix A) to the study, as well as the notice in the university newsletter, indicated that the study involved the formation of a group that does not already exist, and did not include information regarding a meeting agenda. While the initial step of organizing a meeting time and location was completed by the researcher, potential participants may have been apprehensive about the uncertainty of what would occur during the meeting, and uneasy about the scenario presented to them (the creation of an RSO). In qualitative interviews in this study of adults with

autism who had attended college, all four participants indicated anxiety regarding change or uncertainty. It is possible that potential participants felt that attending a meeting in which they did not know what would take place would cause them anxiety.

Lack of encouragement.

Weidle, Bolme, & Hoeyland (2006) found that participants in a study of support groups for adults with autism were not initially interested in joining the groups but that family members insisted that they participate and made certain the participant arrived at the meetings. Jantz (2011) found that one reason adults with AS were likely to seek a support group was because they were encouraged to attend by someone else. In qualitative interviews in this study of adults with autism who had attended college, one participant recognized the benefits of belonging to an RSO for his population, but indicated that he would not have participated. It is possible that this participant would have changed his mind over time had he received encouragement to attend from someone he trusted. It is possible that some potential participants at the research site were initially resistant to participating in the study, and did not have someone to encourage them to rethink their initial reaction.

Perceived lack of group leadership.

In a study conducted by Muller, Schuler, and Yates (2008), adults with AS stressed the importance of membership within autism-related groups, but agreed that it was usually necessary for someone else (who did not have the disorder) to organize and maintain the group. Jantz (2011) interviewed adults with AS regarding their perceptions of, and participation in, support groups. A number of participants indicated that support groups must be moderated by a facilitator in order to ensure that everyone has the opportunity to speak. The invitation to participate in this study did not include information regarding a moderator or group leader. It is

possible that potential participants did not want to attend the meeting because they did not believe there would be a moderator or leader to guide them.

Stigmatization.

There are currently no studies to indicate whether belonging to a group of any kind for persons with AS or HFA caused members to be stigmatized or feel stigmatized. The qualitative interview portion of this study revealed that three of the four participants had apprehensions regarding stigmatization as a result of belonging to an RSO for students with AS or HFA. Participants voiced concerns that membership in an RSO of this nature would mandate disclosure and potential stigmatization. It is possible that potential participants were concerned about being stigmatized, or that they would be forced to disclose their diagnosis to others.

Timing.

Presently, there are no studies regarding persons with AS or HFA and ideal timing of their participation in an RSO for their population. In qualitative interviews in this study of adults with autism who had attended college Frank indicated that he would have waited to join an RSO for students with AS or HFA until his second year to allow himself time to adjust to college. It is possible that potential participants did not want to participate in the proposed RSO because they were attempting to adjust to college life and did not want to add to their schedules, or were about to finish college and did not need to join a group at that point in their collegiate careers.

Qualitative interviews of adults who have attended college.

The insights of adults with Asperger's Syndrome or High Functioning Autism who have been to college were sought regarding student organizations for their population. Interviews were conducted with three men diagnosed with Asperger's Syndrome, and one woman diagnosed with High Functioning Autism. Several themes emerged.

Participants' thoughts regarding belonging to an RSO for students with AS or HFA.

Results of qualitative interviews with adults with AS or HFA who attended college were evenly divided. Two participants would have liked to have participated in a group of this nature, and two did not.

Grandin (1986), Willey (1999), and Prince-Hughes (2002), each discussed the importance of finding other people who were similar to themselves while they attended college. Bebbington and Sellers (as cited in Attwood, 1998) found that adults with AS felt the need to know that there are other people like themselves. Muller, Schuler, and Yates (2008) found that adults with AS stressed the importance of membership within Autism-related groups, which enabled them to meet others like themselves. Graetz and Spampinato wrote that many people with AS seek the companionship of others with the disorder. Results of qualitative interviews are consistent with previous findings. Peggy and Frank indicated an eagerness to meet others with similar challenges and stated they would have joined an RSO for students with AS or HFA.

Current literature does not reveal studies devoted to the experience of students with AS or HFA and their participation in groups for students with disabilities unspecified. Frank indicated that he would have joined an organization for students with all disabilities and indicated a desire to interact with students with diverse disabilities.

Graetz and Spampinato (2008) stated that most adolescents with AS want to socialize with their peers but lack the ability to do so naturally, and find the experience overwhelming and frustrating. Attwood (1998) characterized AS as having core features of "a lack of social skills," and "limited ability to have a reciprocal conversation." Two participants, Carlos and Don, indicated that they would not have joined an RSO for students with AS or HFA because socializing in a group is uncomfortable to them.

As stated earlier, there are presently no studies to indicate whether belonging to a group of any kind for persons with AS or HFA caused members to be stigmatized or feel stigmatized. Carlos and Don both stated that they would not have joined an RSO for students with AS or HFA because they were concerned that membership would mandate disclosure and potential stigmatization.

Participants' perceptions of benefits of belonging to an RSO for students with AS or HFA.

Adults with Asperger's Syndrome or High Functioning Autism who had attended college were asked about their perceptions and experiences regarding student organizations for their population. Participants shared their thoughts regarding the benefits of participating in a group of this nature.

Attwood (1998) stated that many people with AS find friendships with other people who have the same diagnosis. As stated earlier, Grandin (1986), Willey (1999), and Prince-Hughes (2002) each discussed the importance of finding other people who were similar to themselves while they attended college. Bebbington and Sellers (as cited in Attwood, 1998) found that adults with AS felt the need to know that there are other people like themselves. Graetz and Spampinato wrote that many people with AS seek the companionship of others with the disorder. Participant responses supported these findings when they discussed the benefits of belonging to an RSO for students with AS or HFA. Three of the four participants stated that students with AS or HFA would benefit by getting to know other students with similar challenges.

Jantz (2011) found that adults with AS wanted support groups for their populations to provide them with a forum for learning from others' experiences with AS. Graetz and Spampinato (2008) encouraged group meetings for students with AS, and recommended that

students with AS talk to other students with the disorder and identify coping skills and supports that are in place at their institution in order to successfully navigate the college process. Schuch (2010) found that one of the primary benefits of membership in an LGBT organization at a university was that students who participated in the LGBT group had a greater knowledge of resources available to them. Results of qualitative interviews are consistent with previous findings. When discussing the benefits of belonging to an RSO for students with AS or HFA, Frank stated that he believed belonging to a group of this nature would help ensure that members are receiving the classroom, campus, and community services that they need. Peggy indicated that participating in a group would enable members to learn from each other.

Jantz (2011) found that adults with AS indicated they wanted support groups for their populations to provide them with a sense of belonging and a place to learn social skills. Weidle, Bolme, & Hoeyland (2006) found improvement of identity and self-confidence in adolescents with AS who participated in support groups. Garry (Prince-Hughes, 2002) wrote that members of the support group for adults with AS that he participates in are relaxed in each other's company and that some of the members of the group are gaining confidence. Participant insights regarding the therapeutic and emotional benefits to belonging to an RSO for students with AS or HFA are consistent with this literature. Carlos states that he believed members of a group of this nature would be relieved to meet others who are in the same situation as they are, and that members may gain confidence when they interact successfully with other members. Peggy indicated that she believed a benefit to belonging to an RSO for students with AS or HFA would be the ability to learn about emotional issues from other members.

Symes & Humphrey (2010) found that Adolescents with Autism Spectrum Disorder received lower levels of social support from their peers. Muller, Schuler, & Yates (2008) found

that adults with AS and HFA emphasized the importance of attitudinal supports from others, including patience, and caring, tolerance of differences, and willingness to initiate social interactions. One participant in qualitative interviews of adults with autism who attended college shared thoughts that were consistent with these findings. Don felt that a benefit of a group of this nature would be greater awareness on campus regarding autism.

Participants' thoughts regarding challenges that an RSO for students with AS or HFA may face.

Adults with Asperger's Syndrome or High Functioning Autism who had attended college were asked for their thoughts regarding challenges that an RSO for their population would face.

Weidle, Bolme, & Hoeyland (2006) found that young adults with AS were initially reluctant to support groups. Jantz (2011) found that a prevailing reason why individuals with AS were most likely to seek a support group was because they were encouraged to attend by someone else, and would not have attended if left to decide on their own. Qualitative interview participant responses were consistent with these findings. Carlos and Don both indicated that attendance would be the foremost challenge that an RSO for students with AS or HFA would face. This was also evident by the unwillingness of any of the ten potential participants to participate in the phenomenological study of an RSO for students with AS or HFA.

Studies have found that members of groups for persons with AS or HFA have not suffered emotionally and have actually been comforted due to their participation in a group setting. Through an individual case study of a woman with AS who participated in a support group for adults with a diagnosis of Autism Spectrum Disorder, MacLeod & Johnston (2007) found that the participant gained comfort and reassurance from the support group, was not as anxious when she participated in the group as she typically was in similar settings, and felt part

of a common group for the first time in her life. Prior to joining the group, the participant stated she was depressed and suicidal about her condition. Jantz (2011) found that there was no increase or decrease in feelings of loneliness in adults with AS who participated in support groups for their population, but that participants in the study believed support groups were useful overall. Rose & Anketell (2009) found that participation in a group for children and adolescents led to improvement in symptoms of anxiety, depression, aggression, withdrawal, and self-esteem/confidence for its members. In contrast to these findings, two of the participants had expressed concerns regarding potential negative emotional impact. When discussing disadvantages and challenges an RSO for students with AS or HFA might face, Peggy voiced concerns about group members “clashing” or not getting along. Carlos voiced concerns that members may be forced to confront topics they may not wish to and that it could “go really badly,” and cause them “some damage.”

As stated earlier, there are currently no studies to indicate whether belonging to a group of any kind for persons with AS or HFA caused members to be stigmatized or feel stigmatized. Three of the four participants voiced concerns that membership in an RSO for students with AS or HFA could cause stigmatization and would mandate disclosure.

Jantz (2011) found that adults with AS felt that support groups must be moderated by a facilitator in order to ensure that everyone has the opportunity to speak, that group meetings contain a social focus, and are structured with group rules clearly explained. Muller, Schuler, and Yates (2008) interviewed adults with AS and found that they preferred social supports that included structured and facilitated social activities and that someone organize and maintain any group. Qualitative interview participants had varied recommendations for the meeting structure of an RSO for students with AS or HFA. Peggy stated she would like to see a group participate

in social activities and for meetings to be structured, which is consistent with current research. Carlos felt the opposite approach would be more effective and indicated that he would like to see group meetings that did not follow an agenda or contain structured activities, which is in contrast to existing research regarding structure of meetings for a group for persons with AS or HFA. Peggy indicated that an RSO for students with AS or HFA should include discussion topics related to emotional issues, but Carlos voiced concerns about potential emotional consequences of participation in a group of this nature.

Presently, there is no research concerning difficulties within a group of any kind for persons with AS or HFA due to conflicting views regarding the function of such a group. Participants in this study had varied interpretations regarding the function of an RSO for students with AS or HFA. Frank indicated that the main function of an RSO for students with AS or HFA would be members' ability to share and receive practical information. Don believed the function of the group was to assist students with AS or HFA in practical and therapeutic ways. Peggy viewed the primary function of a group of this nature was to provide opportunities for socialization. Carlos indicated through his responses that he believed the primary function of a group of this nature would be group counseling.

Participants' suggestions to assist in the success of an RSO for students with AS or HFA.

Adults with Asperger's Syndrome or High Functioning Autism who had attended college were asked to share their suggestions for the success of a group of this nature.

Jantz (2011) found that adults with AS liked support groups to have a social focus. While participants in this study emphasized socialization, each had different ideas regarding fostering socialization.

Muller, Schuler, & Yates (2008) found that adults with AS and other HFA spectrum disorders recommended that externally implemented social supports for their population include structured and facilitated social activities. When offering suggestions for a student organization of this nature to be successful, Peggy and Frank offered suggestions regarding social activities, which were consistent with these findings.

Muller, Schuler, & Yates (2008) interviewed adults with AS or other autism spectrum disorders and found that the majority of them reported that one-to-one conversations were their favorite means for socializing. “Most participants also noted that small groups – particularly in academic settings – could serve as an effective means of enabling positive social interaction” (p. 182). Carlos echoed these findings when he suggested groups for this population encourage small group or individual interaction in order to foster socialization. Don’s responses regarding one-on-one supports that he would have preferred were also consistent with this research.

As discussed earlier, Muller, Schuler, and Yates (2008) and Jantz (2011) found that adults with AS preferred group meetings that are structured, moderated by a facilitator, and with clearly explained group rules. As Bolick (2004) stated, persons with AS have a preference for predictability. Peggy and Frank’s thoughts and suggestions regarding meeting structure are consistent with this literature. Both indicated that a group would be successful if it contained structured, facilitated activities and a group moderator. Carlos, however, made recommendations in contrast to existing research and literature, recommending that group meetings did not follow an agenda or contain structured activities.

The effects of age and maturity on persons with AS or HFA opinion regarding the joining of a group.

Presently, there is no research regarding maturity and the willingness of persons with Asperger's Syndrome or High Functioning Autism to participate in a group of any kind. Adults with AS or HFA who had attended college were interviewed regarding their current involvement in organizations. Responses were compared to their responses regarding their involvement in organizations when they were in college, in order to determine if their opinions changed as they mature. Three of the four participants interviewed had graduated college within 5 years of this study; therefore, it is not possible to conclude whether age or maturity affected these participants' opinions. Participant thoughts regarding participating in groups for persons with AS or HFA at the present time mirrored their feelings regarding participation in RSOs for their population while they were in college. Participant reasons for participating or avoiding groups of this nature were the same as they were while they attended college. One participant indicated a new reason for participating in a group now, in addition to his original reasons for participation in college.

Additional themes.

Participant responses to the research questions elicited several themes that were not related to the initial research questions. Themes that emerged included participants' desire to meet people who are similar to themselves, level of functioning potentially affecting participants' desire to belong to a group, difficulties transitioning into college, emotional concerns and bullying, participant misconceptions regarding the function and format of the proposed RSO, and other forms of support.

Muller, Schuler, & Yates found that adults with AS and other high functioning Autism spectrum disorders longed for greater emotional intimacy and social connectedness. Participant responses were consistent with this literature. Three participants indicated that they desire individual connections and wish to meet people who are similar to him or her, whether it is someone with common challenges, or someone with common interests.

Barnhill (2001) found a significant positive relationship between IQ and ability attributions for social failure in adolescents with AS, suggesting that higher IQ in a person with AS indicates higher functionality. The researcher noted that two participants, Don and Carlos, did not display outward characteristics of autism upon first meeting them, indicating that they were higher functioning than the other two participants. Don and Carlos were opposed to belonging to a group for their population because they were aware of their difficulties with socialization in groups, and were concerned about being stigmatized. This is consistent with Barnhill, and implies that Don and Carlos's higher functionality causes them to be more aware of their social deficits which in turn causes them to be more wary of social situations.

Attwood (2008) stated that the transition to college is stressful for students with Asperger's Syndrome. Grandin (1986) described the difficulties of her transition to graduate school. Three of the four participants in this study described difficulties with change and transition, which is consistent with the literature.

According to Attwood (1998), people with AS are often excluded, teased or ridiculed. Symes & Humphrey (2010) found that adolescents with autism were significantly more likely to be rejected by their peers and experienced significantly greater frequencies of bullying. Bebbington and Sellers (as cited in Attwood, 1998) found common issues that adults with AS face include feelings of isolation and teasing from colleagues. Shtayermman (2007) found that

adolescents and young adults diagnosed with AS reported a high level of peer victimization, and Carter (2009) found that 64.7 percent of children and adolescents with AS studied had been victimized and shunned by siblings and peers. Responses by participants in this study were consistent with these findings. Participants indicated that they experienced feelings of isolation, depression, and anxiety while they attended college. One participant experienced bullying.

Persons with AS are characterized by Attwood (1998) as having limited ability to have a reciprocal conversation. According to G. Richard (personal communication, November 30, 2011), deficits in executive function are present in persons with Asperger's Syndrome, affecting decision-making and working memory. Persons with AS struggle to process and retain information that is presented to them. When presented with information regarding the proposed registered student organization for students with AS or HFA, the three qualitative interview participants diagnosed with AS struggled to understand the format and function of the group, and failed to understand that group members would have the ability to determine the group's activities. At the onset of the interview, the researcher verbally explained the purpose, function, and structure of the proposed RSO for students with AS or HFA, and explained that members of the group would determine the format of group meetings as well as group activities. The sole participant who understood the purpose of the group as it was explained to her is diagnosed with HFA. Misconceptions regarding the purpose and function of the student organization are not surprising, given characteristics of autism and AS in particular.

Astin (1999) argued that all development, whether it is in the classroom or outside of the classroom, should involve interpersonal interaction, including discussions with faculty and peers, and the formation of commonality groups. Graetz and Spampinato (2008) stated that students with AS are confronted with challenges that do not exist for the typical student. Bolick (2004)

stated that students with AS benefit when individuals come together regularly to help the student with particular challenges. Participant experiences and suggestions were consistent with Graetz and Spampinato and Bolick and were in direct contrast to what Astin considered necessary for development, highlighting the need for enhanced support outside of the classroom for students with autism. Carlos described hours of idle time between classes, with nothing to do and no one to talk to. Peggy described two situations in which challenges with regulating her mood and controlling her impulses, combined with her misunderstanding of socially-appropriate behavior led to her receiving disciplinary action. Don stated that he would have liked to have had a mentor and specialized career guidance while he was in college. Other participants discussed situations where they struggled academically and either benefitted, or would have benefitted, by working with an academic advisor or instructor who was familiar with their unique challenges.

Conclusions

The following conclusions are drawn, based on participant responses in the present study, as well as current literature.

1. Some persons with Asperger's Syndrome or High Functioning Autism are very uncomfortable among groups of people, and would not be interested in joining a Registered Student Organization or support group for their population.
2. Some persons with Asperger's Syndrome or High Functioning Autism enjoy being in groups of people and relish opportunities to socialize among a group.
3. Persons with Asperger's Syndrome or High Functioning Autism may be concerned about becoming stigmatized due to their membership in a Registered Student Organization for their population.

4. Lack of participation/low attendance is the primary challenge that a Registered Student Organization for students with Asperger's Syndrome or High Functioning Autism may face.
5. Some persons with Asperger's Syndrome or High Functioning Autism may recognize benefits to belonging to a Registered Student Organization for their population, but do not wish to participate.
6. Persons with Asperger's Syndrome or High Functioning Autism have differing opinions regarding the function and purpose of a Registered Student Organization or support group for their population.
7. Persons with Asperger's Syndrome or High Functioning Autism have differing opinions regarding the structure and format of meetings for a Registered Student Organization or support group for their population.
8. Persons with Asperger's Syndrome or High Functioning Autism desire to meet others who are like them.
9. Persons with Asperger's Syndrome or High Functioning Autism can misinterpret or forget details (such as time or location of meetings, purpose, or function of the group) regarding a Registered Student Organization or support group for their population.

Implications for Student Affairs Practitioners

Participant responses to the research questions, along with current literature, elicited several themes that were relevant to Student Affairs Practitioners.

1. When promoting an RSO for students with Asperger's Syndrome or High Functioning Autism, it is important to present clear, specific, and concise information in a visual manner to students in order to promote understanding of the format and function of the

RSO for their population, and to diminish the risk for potential participant misinterpretation of group purpose. It is recommended that student affairs professionals consult with a Speech Language Pathologist or other professional with knowledge of autism when developing this information.

2. Students with Asperger's Syndrome or High Functioning Autism may need reminders and/or encouragement to attend RSO meetings and activities.
3. RSOs for students with Asperger's Syndrome or High Functioning Autism require a moderator who does not have autism. It is recommended that the moderator have an understanding of Asperger's Syndrome and High Functioning Autism.
4. Group members should work together to determine the format and function of an RSO for students with Asperger's Syndrome or High Functioning Autism; however, the moderator should ensure that activities promote socialization.
5. Group members should suggest activities that will take place during meetings; however, the moderator of an RSO for students with Asperger's Syndrome or High Functioning Autism should ensure that each meeting has a clear agenda and schedule that is presented to the group in a visual manner.
6. Students with Asperger's Syndrome or High Functioning Autism may benefit by having a student, faculty, or staff mentor.
7. Students with Asperger's Syndrome or High Functioning Autism may benefit by receiving specialized academic and/or career advisement from a faculty or staff member who has an understanding of Asperger's Syndrome and High Functioning Autism.
8. Transitions are often difficult for students with Asperger's Syndrome or High Functioning Autism. It is recommended that campuses implement a comprehensive

program that would assist students with autism who are new to the campus or are experiencing a change (such as a change in housing, employment, or major/department).

9. To promote socialization, encourage students with Asperger's Syndrome or High Functioning Autism to participate in student groups related to their area(s) of interest. Students with Asperger's Syndrome or High Functioning Autism who are resistant to joining an RSO for their population may be open to joining a group related to their area of interest.
10. Students with Asperger's Syndrome or High Functioning Autism have different criteria for, and understanding of friendship than the typical student population. Friendships are based mainly on common areas of interest. Some students with autism may believe another student is their friend when there is no actual friendship.
11. Students with Asperger's Syndrome or High Functioning Autism may suffer from comorbid mood disorders. Because persons with autism have difficulty expressing their own feelings, symptoms of these disorders may present differently than for the general population. Suicidal ideation may not be as apparent in students with autism.

Recommendations for Further Study

Participant responses to the research questions elicited several themes that suggest further study.

1. It is recommended that studies be conducted to determine whether belonging to a group of any kind for persons with Asperger's Syndrome or High Functioning Autism caused members to be stigmatized or feel stigmatized.

2. It is recommended that research be conducted to explore whether difficulties arise within groups for persons with Asperger's Syndrome or High Functioning Autism due to conflicting views regarding the function of a group or the structure of its meetings.
3. It is recommended that research be conducted to explore whether age or maturity influence a person with Asperger's Syndrome or High Functioning Autism in regards to their decision to become involved in a group.
4. It is recommended that research be conducted to determine if there is a correlation between levels of autism symptomology/functionality and interest in group participation.
5. A review of the efficacy of other forms of supports available to students with Asperger's Syndrome or High Functioning Autism in the collegiate setting is recommended.
6. It is recommended that research be conducted to explore when in their collegiate career students with Asperger's Syndrome or High Functioning Autism would be most able or most likely to participate in an RSO for their population.
7. It is recommended that research be conducted to explore levels of interest persons with Asperger's Syndrome or High Functioning Autism may have in participating in groups for persons with disabilities unspecified.
8. It is recommended that research be conducted to study the experience of persons with Asperger's Syndrome or High Functioning Autism that belong to groups for persons with disabilities unspecified.
9. It is recommended that research be conducted to determine whether student groups comprising of members with Asperger's Syndrome or High Functioning Autism can successfully complete the required processes for establishment of registered student organizations on college campuses.

Summary

As college campuses welcome an increasing number of students with Asperger's Syndrome or High Functioning Autism, student affairs professionals must learn to adapt their skills to challenge and support this population. As student affairs professionals instinctively encourage the formation of social groups and campus involvement to ensure an enriching learning experience, it is important for these professionals to be aware of the effects of autism and whether or not an individual with autism is comfortable being involved in campus life in the same way that a neurotypical student is able to be.

Findings of this study reveal that some persons with AS or HFA are uncomfortable in group settings but are in need of, and receptive to, receiving other forms of social supports. Moreover, some students with autism are eager to participate in an RSO for their population, but have differing opinions regarding the purpose, function, and format of such an organization. When establishing social groups for students with AS or HFA, it is important that a neurotypical person with an understanding of autism moderate group meetings, and that confidentiality is emphasized to assuage concerns regarding stigmatization.

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APPENDIX A
Invitation to Participate

You are invited . . .

Dear Student,

You are invited to participate in the formation of a student organization for students with Autism/Asperger's Syndrome.

The process of forming the group will be part of a research study that will assist other campuses in the formation of student organizations for students with autism on their own campuses.

This is a unique opportunity to be involved in establishing a group and defining it.

Please come to the first meeting on Sunday, January 29, 2012 from 4pm to 5:30pm at the Greenup Room in the MLK University Union. The Greenup Room is on the third floor of the east wing of the University Union. Details of the study will be discussed at the meeting.

If you would like to participate but are unable to attend, please contact Jennifer Smith at jlsmith@eiu.edu.

APPENDIX B

University Newsletter Posting

STUDENT GROUP FOR STUDENTS WITH AUTISM TO MEET

Students of EIU who have been diagnosed with autism are invited to participate in the formation of a student organization for students with Autism or Asperger's Syndrome. The first meeting will be held from 4 to 5:30 p.m. Sunday, Jan. 29, in the Greenup Room in the MLK Jr. Union. The Greenup Room is on the third floor of the east wing of the union.

This is a unique opportunity for students to be involved in establishing a group and defining it. This student group would be among the first of its kind in the nation.

The process of establishing the group will be part of a research study that will assist other campuses in the formation of student organizations for students with autism on their own campuses. Details of the study will be discussed at the meeting.

Students who would like to participate in the group but are unable to attend the first meeting may contact Jennifer Smith at jlsmith@eiu.edu.

JENNIFER L. SMITH, College Student Affairs

Posted: Jan 19, 2012

APPENDIX C
Interview Questions

Demographic Questions:

- How old were you when you attended college?
- How old are you now?
- Where did you go to college?
- Did you graduate?
- Did you live on campus?
- Did you live alone or with someone (if so, who with)?
- Did you register with disability services and/or receive any accommodations while in college?

Possible Need for Services:

- Did you have friends when in college?
- If yes, approximately how many?
- Were those friends also in school?
- Describe those first few weeks of college
- Describe your college experience overall emotionally
- Describe your college experience overall academically

Perceptions of Student Groups for AS/HFA Population:

- Thinking about who you were when in college, if there was the opportunity, would you have joined a group for students with autism?
- Why or why not?
- What do you think would be the benefit of such a group?
- What do you think would be the disadvantage of such a group?
- What challenges could you foresee if a group was trying to be established on a campus?
- Do you have any suggestions to help a group like this be successful?
- Thinking about who you were when in college, if there was the opportunity, would you have joined a group for students with the same areas of interest as you?

Effects of Age and Maturity on Group Participation:

- Would you join a group now?
- Why or why not?

Do you know of someone else with Autism who went to college and may be willing to allow me to interview him or her?

APPENDIX D

Consent to Participate in Research

CONSENT TO PARTICIPATE IN RESEARCH

Qualitative Study of the Opinions Regarding Registered Student Organizations for Students with Autism

You are invited to participate in a research study conducted by Jennifer Smith from the Department of Counseling and Student Development at Eastern Illinois University.

Your participation in this study is entirely voluntary. Please ask questions about anything you do not understand, before deciding whether or not to participate.

You have been invited to participate in this study because you attended college and have self-identified as having Autism or Asperger's Syndrome.

• PURPOSE OF THE STUDY

The purpose of the present qualitative study is to gain the perspectives of former college students who have Asperger's Syndrome or High-Functioning Autism regarding the challenges of belonging to a student organization for their population during the time in which they were enrolled in college. The data obtained will be beneficial to student affairs or disability services professionals when considering the formation of a group for students with Asperger's Syndrome or High-Functioning Autism on their campuses.

• PROCEDURES

If you volunteer to participate in this study, you will be asked to allow the researcher to interview you.

Interviews will be audiotaped to ensure accuracy of statements.

• POTENTIAL RISKS AND DISCOMFORTS

There is limited risk to you as a participant of this study. It is unlikely that you will suffer any adverse psychological affects as a result of participating in this group. Though it is unlikely, some participants may experience some discomfort during the interview.

You will have the option of discontinuing your participation in this study at any time.

• POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

Benefits of participation include the possible catharsis of discussing past frustrations, as well as contributing to the improvement of quality of life for others with the same disorder. The results of this study will assist other institutions in the formation of registered student organizations for this population of their own campuses.

• CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of the use of an assigned pseudonym for all participants. The researcher will record information on the researcher's personal computer in a password protected folder. Audio tapes will be transcribed and transcriptions will be stored on the researcher's personal computer in a

password protected folder. Each subject will be given a pseudonym and actual names will not be transcribed. Only the researcher will have access to the audio tapes, which will be stored in a locked safe in the researcher's home and will be destroyed after three years. Transcriptions, informed consent forms, and any other records will be destroyed after three years.

- **PARTICIPATION AND WITHDRAWAL**

Participation in this research study is voluntary and not a requirement or a condition for being the recipient of benefits or services from Eastern Illinois University or any other organization sponsoring the research project. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind or loss of benefits or services to which you are otherwise entitled. There is no penalty if you withdraw from the study and you will not lose any benefits to which you are otherwise entitled.

- **IDENTIFICATION OF INVESTIGATORS**

If you have any questions or concerns about this research, please contact:

Dr. Rick Robert, Faculty Sponsor
 Department of Counseling and Student Development
 217-581-2400.
 rlroberts@eiu.edu

- **RIGHTS OF RESEARCH SUBJECTS**

If you have any questions or concerns about the treatment of human participants in this study, you may call or write:

Institutional Review Board
 Eastern Illinois University
 600 Lincoln Ave.
 Charleston, IL 61920
 Telephone: (217) 581-8576
 E-mail: eiurb@www.eiu.edu

You will be given the opportunity to discuss any questions about your rights as a research subject with a member of the IRB. The IRB is an independent committee composed of members of the University community, as well as lay members of the community not connected with EIU. The IRB has reviewed and approved this study.

I voluntarily agree to participate in this study. I understand that I am free to withdraw my consent and discontinue my participation at any time. I have been given a copy of this form.

 Printed Name of Participant

 Signature of Participant

 Date