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## From bullies to brotherhood : an exploratory qualitative study of Aspergian adolescents' perspectives on friendship

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Michelle Kaye  
(Orion Academy, Moraga CA),  
From Bullies to Brotherhood: An  
Exploratory Qualitative Study of  
Aspergian Adolescents' Perspectives  
on Friendship

### **Abstract**

This study explored how Aspergian adolescents attending a specialized school perceive and understand friendship. This exploratory qualitative study aimed to further knowledge of how Aspergian adolescents understand friendship for clinicians, parents, teachers and researchers. Another primary goal of this project was to collect the views and perceptions of Aspergian adolescents and to disseminate the findings to the participants and other Aspergian adolescents.

The primary goal of this research project was to examine how being educated in a specialized school affects how Aspergian adolescents understand the concepts surrounding friendship. This study was conducted at Orion Academy, an 8<sup>th</sup>-12<sup>th</sup> grade preparatory high school for students with Asperger's Disorder and Non-verbal learning disability located in Moraga, California. Data was collected through three focus groups consisting of eight participants; four 8<sup>th</sup> graders, two 9<sup>th</sup> graders and two 12<sup>th</sup> grade students.

This study found that Aspergian adolescents both desire and are able to make and maintain long-lasting and intimate friendships. Social skills courses, class size and class composition at Orion Academy were found to positively impact students' ability to make and maintain friendships. Participants also benefited from the lack of bullying at Orion Academy.

FROM BULLIES TO BROTHERHOOD:  
AN EXPLORATORY QUALITATIVE STUDY OF ASPERGIAN ADOLESCENTS'  
PERSPECTIVES ON FRIENDSHIP

A project based upon an investigation at Orion Academy, Moraga  
California, submitted in partial fulfillment of the requirements for  
the degree of Master of Social Work.

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2011

## ACKNOWLEDGMENTS

First and foremost I would like to thank the teachers, administrators, staff and students at Orion Academy for their collaboration on this research project. Thanks in particular to the eight participants who gave their time and tremendous insight. A special thanks to Dr. Andrew Schlegelmilch for all of his hard work making sure that this research project could take place.

Thanks to Jeff Smith for all of his encouragement and endless support. Also thanks to my fabulous thesis advisor, Mariko Ono, for reading endless drafts and emails, answering my many questions, providing insight and guidelines and also for alleviating my stress and anxiety by reminding me: “You will get through this!” You were right. Thanks so much.

Special thanks as well to Andrew, whose humor, wisdom and earnestness was the inspiration behind this project.

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## **CHAPTER I**

### **Introduction**

Andrew is playing with Legos. As he simulates a fight between two Lego airplanes, he tells me about how sad he is. Andrew has the same concerns as most 16-year-old juniors: what's going to happen after high school; does the girl he likes like him back; will he be elected to student council? But Andrew isn't like most 16-year-olds. Andrew is sad today because he feels like his friends aren't real friends. He's starting to sense that maybe he is different from classmates his age. As he crashes Legos into each other, we strategize about how to fit in, get people to like him and make and maintain the kind of friendships he yearns for.

Andrew has Asperger's Disorder (AD). Asperger's is on the Autism Spectrum. The primary symptom of Asperger's is that individuals suffer from "impairment in social, occupational and other areas of functioning" (American Psychiatric Association [*DSM-IV-TR*], 2000, p. 76). Research on Asperger's has shown that many adolescents with AD experience loneliness due to a discrepancy between their desire to have friendships and their ability to make and maintain them (Bauminger et al., 2000; Lasgaard et al., 2010).

During my work with Andrew and other Aspergian adolescent boys at a public high school during my first year field placement, I found that loneliness, due to an inability to establish and maintain meaningful friendships, was one of the primary presenting problems for my clients. When I tried to study this phenomenon, I found that almost all of the research on the topic of Asperger's and friendship focused on children attending mainstream schools. From my

research I discovered that there are other private options for children with AD if their parents and caregivers could afford them. One of these institutions is Orion Academy, located in Moraga California, about an hour and half away from San Francisco. Orion Academy is the first college-prep high school for students diagnosed primarily with Asperger's Disorder ("Orion Academy Asperger's—NLD High School", n.d.).

The purpose of my research study is to explore how friendship is understood by Aspergian adolescents who attend Orion Academy, a specialized school comprised primarily of students with the same or a similar diagnosis. The primary goal of my research is to examine what impact this specific social and educational environment has on how teens with Asperger's syndrome understand the concepts surrounding friendship.

In my research, I have found some discrepancy around the correct title for Asperger's. It is referred to as Asperger's Disorder, Asperger disorder, Asperger's syndrome, Asperger's Syndrome and simply Asperger's in various publications. In the *DSM-IV-TR* (American Psychiatric Association, 2000), it is referred to as Asperger's Disorder. Therefore that is how I will refer to it in this study. I will also employ the acronym: AD. I will use ASD to refer to autism spectrum disorders. HFA will sometimes be employed as a substitute for High Functioning Autism. Nonverbal learning disability is also mentioned several times in this study, and will occasionally be shortened to its common acronym: NLD.

According to the tenets of self-psychology, in order to become a coherent self, people must feel that they are understood by others (Kohut, 1984). Although friendship is a highly subjective concept, it is something that almost all people seek as part of finding and maintaining a healthy self. Friendship becomes especially important during adolescence, as youth experience

identity confusion and look to their peers to understand who they are (Erikson, 1963).

Adolescents with Asperger's, who experience no cognitive deficiencies, appear to have the same desire to make and maintain friendships as their neurotypical peers.

Asperger's has only been diagnosable since 1994. As a fairly new diagnosis, there is much to be understood about Asperger's. Asperger's is currently being considered for removal from the DSM-V due to inconsistency with how it is delineated from High-Functioning Autism ("Proposed Draft Revisions to DSM-5", 2011). This change may influence the amount of upcoming research done on this specific diagnosis. This study hopes to augment the literature on quality of friendships in Aspergian adolescents. My study uses a strength-based approach to facilitate discussion from participants about what friendship means to them in their own terms. Friendship has been shown to positively influence loneliness, anxiety and social skills impairment that Aspergian adolescents (Bauminger et al., 2008) as well as other adolescents and individuals undergo in psychosocial development. Developing an understanding of what friendship looks like for adolescents with Asperger's could aid practitioners and researchers in building new, tailored intervention models for this population.

I would like to disseminate my thesis to parents of my participants and other members of the Orion Academy community. Since there are no cognitive deficiencies in AD individuals according to the American Psychiatric Association (*DSM-IV-TR*, 2000), the adolescents themselves could use my study to inform them of their ability to engage in peer relationships. By disseminating my thesis to study participants directly, I hope to be able to empower a population that is often disempowered due to age and disability.



In the next chapter, I will review literature relevant to this topic. In the following Methodology chapter, I will outline the methods used in conducting this research study. The following Findings chapter will outline the major outcomes of this research. My research study will end with a discussion of strengths and limitations of my study and how the findings of this study relate to the previous research conducted on this topic.

## **CHAPTER II**

### **Literature Review**

My research study examines how Aspergian adolescents perceive friendship. The ability to formulate and maintain friendships is one of the greatest challenges for people with a diagnosis of Asperger's. As both Aspergian and neurotypical children reach adolescence, friendships become an important part of identity formulation. My research will be conducted at Orion Academy, an 8<sup>th</sup>-12<sup>th</sup> grade preparatory school for children with Asperger's and Non-verbal learning disabilities. The purpose of my research study is to explore how Aspergian adolescents attending this specialized school comprised primarily of students with the same or similar diagnoses understand friendship.

My research falls into the following categories: friendship, friendship in adolescence, Asperger's Disorder, social skills, anxiety, loneliness, depression, negative social consequences, friendship in adolescents with Asperger's and school friendships in adolescents with Asperger's.

#### **Friendship**

The Stanford Encyclopedia of Philosophy defines friendship as "a distinctively personal relationship that is grounded in a concern on the part of each friend for the welfare of the other, for the other's sake, and that involves some degree of intimacy" (Helm, 2009). However, this definition doesn't come close to encapsulating the concepts that most of us prescribe to friendship. For most people, friendship cannot be defined, since it is something we experience and feel on an unconscious level. In my study I will strive to have adolescents in this study define it themselves, with the understanding that friendship is an arbitrary and indefinable idea.

Most of us have many different kinds of friendships, some of which are intimate and others of which are more distant. Friendship is culturally and even regionally specific. What a friend looks like or should look like is also highly dependent on age, grade level and maturity. Significantly for my study, what friendship does or should look like is also dependent on a person's cognition and (dis)ability. Friendship is a completely subjective concept. However, it is human nature to prescribe the ideas that we have of friendship onto those people around us. In my research, I am interested in discovering what ideas and concepts Aspergian adolescents independently prescribe to friendship, without inserting a preconceived idea of friendship upon them.

The theory of self-psychology is a useful psychological model for understanding the importance of friendship. Self-psychology differs from the psychoanalytic theories that preceded it because it focuses on the whole self and the self's experience in the world rather than on the objective functioning of the mind. Heinz Kohut, the founder of self-psychology, described the self as divided into three poles: the grandiose pole, the pole of the idealized parent, and the pole of twinship. Poles can be thought of as ideals, each one functioning as a distinct pathway into the self with its own energy and needs (Flanagan, 2008). In order to develop a coherent self, Kohut thought that the self had to take in selfobjects related to all three of these poles. A self-object is a whole or a part of a person that is internalized by the self. According to the tenets of self-psychology, people must develop selfobjects that offer twinship, mirroring and acknowledgment of the grandiose self (Flanagan, 2008, p. 171). In other words, people need to experience relationships that make them feel important, parented or taken care of and understood or sympathized with.

The twinship pole refers to every human being's need to feel that there are others in the world like us. Unlike the grandiose and the idealized parent poles, which can be retrieved through mirroring, the twinship pole is "sustained simply by the presence of someone (known) to be like (them)...to understand...and be understood" (Kohut, 1984, p. 196). Kohut (1984) theorized that people seek "a selfobject that will make itself available for the reassuring experience of essential alikeness" (p. 193). In order to experience twinship, people must find others who they feel akin to. They must then be able to internalize this feeling of likeness as a selfobject. Twinship helps us avoid feeling weird, isolated, or in extreme cases like the self is being unraveled. Twinship gives us a feeling of "belonging and legitimacy" (Flanagan, 2008, p. 178).

Kohut's twinship pole helps us to understand the importance of friendship. Latency age children seek this likeness through the imitation of adult skills. As children reach adolescence and then adulthood, they begin to have their twinship needs met through romantic relationships and friendships.

### **Friendship in Adolescence**

Social and developmental psychology is another useful lens to analyze friendship. In *Childhood and Society* (1963), Erik Erikson describes the eight stages of man—a developmental sequence in which an individual masters (or fails) certain tasks in order to achieve the next phase of living. The fifth stage, occurring after puberty, is "identity vs. role confusion" (Erikson, 1963, p. 261). Erikson (1963) theorized that pubescent and post-pubescent youth could no longer rely on the identities they had formulated in childhood. According to Erikson, due to changing bodies and emerging sexuality, youth experience identity confusion. In an effort to find and

understand their new identities, youth become concerned with "what they appear to be in the eyes of others" (Erikson, 1963, p. 261). Erikson theorized that fidelity gave youth their ego strength and that this feeling of fidelity could only be felt within the "social forces of a true community" (Erikson, 1968, p. 235). According to this theory, the primary task of adolescence is to integrate the self that youth see in the eyes of others with the person they feel that are inside.

Erikson's (1963) conceptualization of the psychosocial tasks of youth helps explain some of the behaviors and preoccupations witnessed by anyone working with adolescents. Youth can become "remarkably clannish and cruel in their exclusion of all those who are different" (Erikson, 1963, p. 262). Adolescents are deeply concerned with "who is 'in' and who is 'out'" (Berzoff, Melano, Flanagan & Hertz, 1996, p. 115). According to Erikson, a young person who does not experience intimacy in adolescence is prone to experiencing a "deep sense of isolation" (1968, p. 136) later in life. I am focusing my study on the adolescent population (defined by Erikson as ages 11-18) because this is an age when formation of friendship is of crucial importance. I have chosen the ages of 13-18 because these are the ages when children are typically in secondary education.

### **Asperger's Disorder**

Although Asperger's Disorder did not enter the Diagnostical Statistical Manual (DSM) and thus, become formally diagnosable until 1994, it was actually discovered by Hans Asperger in 1944 when he noticed that there was no medical explanation for the cluster of symptoms he saw in some of his young male patients (Burton, 2010). The word "autism" was historically used to describe people with schizophrenia. Leo Kanner first used it to describe people with autism in *Autistic Disturbances of Affective Contact* (1943). Although they were working

simultaneously, Asperger and Kanner were unaware of each other. While Kanner's findings enjoyed instant recognition, Asperger's findings remained relatively obscure outside the German-speaking world for decades. In 1981 Lorna Wing; author, researcher and parent of an autistic child, discovered and popularized Asperger's findings. The description of Asperger's Disorder, based on the findings of Hans Asperger, described in Wing's (1981) first paper on the subject is consistent with the description in the current edition of the DSM-IV-TR. According to the National Institute of Neurological Disorders (2007), Asperger's affects 1 in 5,000 children, with 63 per 10,000 people having some form of autism spectrum disorder (Hyman, Rodier & Davidson, 2001). More recent data shows that an average of one in every 110 children born in the US has an Autism Spectrum Disorder (Rice, 2006).

Asperger's Disorder (AD) is one of several autism spectrum disorders (ASD). ASD diagnoses include Asperger's, classic autism, Rett's Disorder, Pervasive Developmental Disorder Not Otherwise Specified (or atypical autism) and Childhood Disintegrative Disorder. According to the American Psychiatric Association (*DSM-IV-TR*, 2000) unlike classic autism, Asperger's includes "no clinically significant delays in language...no clinically significant delays in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior...and [there is] curiosity about the environment in childhood" (p. 75).

Mothers were historically blamed for causing ASD by being overly cold and dismissive to their infants (Szatmari, 2003, p. 173). Although there is still much speculation about what causes ASD, this theory has been disqualified. ASD is now known to be neuropsychiatric in nature with a genetic component (Szatmart, 2003, p. 174). This theory is consistent with the

posturing of Hans Asperger (Wing, 1981). The theories that ASD can be caused by "measles, mumps, and rubella vaccine" (Szatmari, 2003, p. 174) have been debunked.

There has been much debate over the difference between high-functioning autism and Asperger's Disorder. As part of a move to streamline diagnoses, the most recent online draft of the upcoming *DSM-V* lists Asperger's as being "subsumed into an existing disorder: Autistic Disorder" ("American Psychiatric Association DSM-5 Development", n.d.). In the rationale for this change, the American Psychiatric Association acknowledges that the existence of the diagnosis has "widened recognition of autism spectrum disorder (ASD) in combination with good language and intelligence" ("American Psychiatric Association DSM-5 Development", n.d.). The researchers then went on to argue that the diagnosis is used "loosely with little agreement" ("American Psychiatric Association DSM-5 Development", n.d.). The primary criteria used to differentiate autism and Asperger's is that autistic children experience language delays and communication defects. However, since "language delay is not a necessary criterion for Autistic disorder" the diagnosis of Asperger's is not deemed necessary ("American Psychiatric Association DSM-5 Development", n.d.). Although Asperger's differs greatly from classic autism in terms of interest in the social environment, this quality may be present in high-functioning autism as well.

The proposed change in the *DSM-V* has created controversy in autism and Asperger's communities. The senior counsel for the advocacy group Disability Rights California, Melinda Bird, argued that this change will help children qualify for special education services as parents won't have to spend "unnecessary time arguing whether a child meets every one of these nuanced

criteria" (Abramson, 2010). On the other side of the debate, the Asperger's Association of New England argued:

The Asperger's diagnostic criteria, although at times admittedly ambiguous, has created a recognizable profile enabling people to identify...a distinct range of strengths and challenges, which has led patients to seek professional help and clinicians to provide a clinically useful diagnosis for patients. (McLeod & Sabian, 2010)

They further argue that people have found pride and identification in the word Asperger's and that it is disempowering to strip it of its meaning (McLeod & Sabian, 2010).

At the time of this study, the *DSM-V* has not yet been released so my research will focus only on adolescents with an Asperger's diagnosis, not one of high-functioning autism or any other diagnosis, as per the *DSM-IV-TR* (American Psychiatric Association, 2000) criteria. I have a bias toward this diagnostic label because it carries meaning to individuals with Asperger's and thus should remain an independent diagnosis. I agree with the position of the Asperger's and Autism Association that removal of the independent diagnosis in the *DSM-V* could be disempowering to individuals with Asperger's as it strips them of a diagnosis they may have worked to identify with.

The literature on Asperger's often focuses on children with ASD and not only children who strictly have an Asperger's diagnosis. Because of the pending *DSM-V* removal and the way that these diagnoses are often lumped in the literature I have chosen to include both AD and ASD in my literature review. As discussed in the Introduction, I will refer to the diagnosis as Asperger's Disorder, Asperger's or AD.

John Elder Robison, an Aspergian adult who blogs, writes and lectures about Asperger's, published a guidebook this year for "Aspergians, Misfits, Families & Teachers" (Robison, 2011, title page). In this guidebook, Robison (2011) intersperses stories about his own challenges



growing up Aspergian with practical advice for children on the spectrum. Robison explained his terminology preference in this way:

The phrase, “have Asperger's” is misleading because it makes Asperger's sound like a disease or an injury...Saying you “have” something implies that it's temporary and undesirable. Asperger's isn't like that. You've been Aspergian as long as you can remember, and you'll be that way all your life. It's a way of being, not a disease. That's why I say, “I am a person with Asperger's.” Many of us shorten this by saying we're Aspergians, or Aspies. (p. 12)

Since my research is strength-based and seeks to include and empower voices from the Aspergian community, I will employ the term "Aspergian" as often as possible throughout my research and will attempt not to refer to participants as having Asperger's.

In this research study I will also refer to people who do not fall into the autism spectrum using the term “neurotypical.” The term “neurotypical” has been coined by people within autistic and Asperger's communities to replace the use of the term “normal”, since the use of the word normal implies that ASD individuals are abnormal. Since this research study aims to use the words and stories of AD adolescents themselves to examine this topic, I will adopt the use of term “neurotypical”, since it emerged from and been adopted by ASD communities.

## **Social Skills**

The primary symptom of AD is that individuals suffer from “impairment in social, occupational and other areas of functioning” (American Psychiatric Association, 2000, p. 76). The first diagnostic criterion for Asperger’s is: “qualitative impairment in social interaction” (American Psychiatric Association, 2000, p. 77). According to a study on this population that examined 40 children ages 3-18, “social skill deficits were variable but remained the greatest challenge for these intellectually bright and verbal children” (Church, Alisanski & Amanullah, 2000, p. 1).

Wing (1981) offered the following explanation for why AD children had difficulty with social skills: "(Social) rules are unwritten and unstated, complex, constantly changing, and affect speech, gesture, posture, movement, eye contact, choice of clothing, proximity to others, and many other aspects of behavior" (Social interaction section, para. 1). When viewed from this perspective, it seems impossible that any of us are able to master social skills and it is easy to understand how many moments or situations are difficult for someone with impaired neurocognitive functioning.

Brain research on people with Asperger's has found deficits in "perception of facial expression and eye gaze" (Stewart, 2007, p. 10). Lack of ability to read non-verbal cues contributes to a lack of social skills in Aspergians. Robison (2011) also discussed how neurological differences in the Aspergian brain account for social skills deficiencies. He explained that an Aspergian brain doesn't respond as effectively to social signals as a neurotypical brain: "We see the smile, just like every other kid. After all, there's nothing wrong

with my eyes. The difference is, our brains don't respond to a smile the same way as everyone else's" (Robison, 2011, p. 82).

Church et al.'s study (2000) found that preschool children with Asperger's were "slow to warm" and were often on the periphery of activities. AD elementary school children were viewed as stiff and divided into two categories, either too quiet and unassuming or too exuberant and "in your face" (Church et al., 2000, p. 14). For the middle and high school children in the Church et al. study, although social skills impairment had improved, it was still seen as the greatest challenge by parents and teachers. This study indicated that as children reached puberty, the disparity between social skills in AD and neurotypical children increased.

Robison (2011) highlighted social skills as one of the most important, teachable things that can help an Aspergian to be more successful at both work and life. Robison explained why it is especially important for young Aspergians to learn social skills:

When you are young, you have not yet made a reputation in your community. You're an unknown quantity. If you act strange, people will be very wary because they don't know what to make of you. They'll be quick to assume you belong in a cage, under restraint. Later in life, strange behavior will be dismissed as harmless eccentricity. So the stuff that gets you chased out of town at sixteen gets laughed off at forty-six. In adulthood, the focus shifts from superficial attributes to your actual accomplishments. That's a much better place for an Aspergian, because our sharply focused intelligence often gives us special abilities. (p. 22)

## **Anxiety**

Anxiety is one of the most prevalent problems for ASD adolescents and children. Research indicates that AD adolescents have higher rates of anxiety than their neurotypical peers (Russell & Sufronoff, 2005; Kuusikko et al., 2008; White, Oswald, Ollendick & Scahill, 2009). Ghaziuddin (2002) found that anxiety was the most common presenting problem for ASD children. White et al. (2009) found that up to 84% of ASD children experience high levels of

anxiety. Shtayermman (2008) found that 30% of Aspergian children and young adults met the criteria for Generalized Anxiety Disorder.

Kuusikko et al. (2008) compared Social Phobia and Anxiety Inventory scores from children with High-Functioning Autism and Asperger's (HFA/AD) to neurotypical children. This study concluded that children with high-functioning autism and Asperger's Disorder have higher rates of both behavioral avoidance and evaluative social anxiety. Kuusikko et al.'s study also showed that while for neurotypical children behavioral avoidance and evaluative social anxiety decrease with age, these increase in HFA/AD children. Russell and Sufronoff (2005) examined this phenomenon further in a study comparing the levels of anxiety of AD children to "normally developing children and clinically anxious children" (p. 634). Russell and Sufronoff found that children with AD showed similar levels of anxiety to children diagnosed with clinical anxiety.

Kuusikko et al.'s (2008) study highlighted the fact that it is often difficult to distinguish the characteristics of ASD from the characteristics of anxiety. White and Roberson-Nay's (2009) study supported this evidence, concluding that "it is often very difficult to distinguish other Axis I conditions, such as anxiety disorders, from the ASD itself" (p. 1012). Both studies suggested that anxiety exhibits itself differently in AD children than in neurotypical children and therefore may not be as readily diagnosed or treated.

White and Roberson-Nay's (2009) study found that when anxiety was present in ASD children, it negatively influenced children's desire to engage in activities with their peers. This research indicated that anxiety can be caused by a lack of interest or ability to socialize with peers and that anxiety may cause ASD children to become even more socially withdrawn.

Robison (2011) made a connection between anxiety experienced by AD children and neurological differences in the Aspergian brain. According to Robison, AD children's deficiencies in understanding social cues can make them anxious because they feel unable to predict or understand the world around them. Robison explained:

When you can't read the unspoken messages of love, all you have to go on are words and observed behaviors. If my life is a guide, those two ways of communicating messages can be sharply at odds with each other, something that paints a disturbing and troubling picture to an Aspergian kid. (p. 90)

### **Loneliness**

White and Roberson-Nay (2009) found that "youth with ASD who reported experiencing elevated anxiety also reported experiencing social loneliness" (p. 1011). White and Roberson-Nay also found that these children did not have high levels of emotional loneliness, indicating that although they might desire to have more social relationships with peers; their emotional needs were met through other relationships in their lives.

Bauminger and Kasari (2000) defined loneliness as "linked to the basic ability to *know* about relationships and to *feel* and experience emotions vis-à-vis this knowledge" (p. 447). Thus they argued that the existence or non-existence of feelings of loneliness in ASD children contributed to the debate about whether ASD is based on cognitive or emotional deficiencies (Bauminger & Kasari, 2000). An existence of social-cognitive loneliness in children with ASD indicates that they perceive a "gap between...actual and desired social status" (Bauminger & Kasari, 2000, p. 448). Bauminger and Kasari found that children with ASD do feel lonely, suggesting that they do have a desire for friendships and that their deficiencies are based on cognitive abilities to formulate them. Robison (2011) wrote that Aspergian children did notice when they were being rejected. Robison wrote, "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" (2011, p. 86).

ASD adolescent boys have been found to have higher rates of loneliness than their neurotypical peers (Lasgaard et al., 2010). Twenty-one percent of the children in the Lasgaard et al. (2010) study described themselves as often or always lonely. Like Bauminger et al. (2000), Lasgaard et al. showed that these children had a desire to have social relationships, and were aware when this desire was unmet. This study also found that children who perceived that they had social support from peers, parents and friends were less likely to feel lonely. The Lasgaard et al. study showed that an Aspergian child who perceives that s/he has a close social support can feel less lonely, regardless of any outside opinion about the relationship.

## **Depression**

Yeung's (2009) dissertation found that 22% of AD adolescents showed signs of depression. Shtayermman's (2008, p. 99) study found evidence confirming that around 20% of AD adolescents and young adults met criteria for Major Depressive Disorder, as defined by the *DSM-IV-TR*. Perhaps due to social skills deficits, empirical evidence indicates that Aspergian adolescents suffer from greater rates of loneliness, depression and anxiety than their neurotypical peers.

Robison (2011) discussed depression as one of the possible negative consequences of Asperger's. He wrote about how his feelings of inadequacy both academically and socially led to him feeling depressed and defeated. This depression eventually led to Robison's decision to drop out of high school.

## **Negative Social Consequences of Asperger's**

Aspergian children and adolescents often experience bullying, victimization and teasing at school and at home (Carter et al., 2009; Little, 2002; Shtayermman, 2007, 2008). Little (2002) found that 94% of children and adolescents with Asperger's had been victimized by peers and siblings. Little's study, which based its evidence on a large national survey of mothers of AD children and children with Non-verbal learning disorders, showed that three-quarters of these children had been hit and emotionally bullied in the past year. The Little study also found that a third of these children had not been invited to a single birthday party all year. Carter et al. (2009) found that nearly two-thirds of Aspergian children were bullied by their peers. Shtayermman (2007, p. 98) also found high levels of victimization in Aspergian children. Further, Shtayermman (2008) found that 50% of AD children had clinically significant levels of suicidal ideation. The studies by Shtayermman (2007; 2008) suggest that there is a high correlation between AD children being victimized at school and at home and suicidal ideation.

## **Friendship for Aspergian Adolescents**

The research indicates that AD children experience loneliness due to a discrepancy between their desire to have friendships and their ability to make and maintain them (Bauminger et al., 2000; Lasgaard et al., 2010). Yeung (2009) also showed a relationship between loneliness and friendship in AD adolescents in mainstream school settings. In this regard, friendship can be seen as a preventive measure against the negative consequences of being Aspergian. Friendship has also been found to improve communication skills for children with high-functioning autism (Bauminger et al., 2008). Bauminger et al. (2008, p. 135) found that "friendship follows a developmental trajectory in autism and may enhance social interaction skills." This study

indicated that not only do friendships decrease loneliness and anxiety in AD children, but they also may positively influence their social skills (Bauminger et al., 2008).

The research demonstrated that although Aspergian middle and high school children do have friendships, these friendships look very different from the friendships formed by neurotypical children (Church, 2000). Four of the eight middle school children in Church et al.'s (2000) study attested to having a best friend, but this friendship was "seen by parents as superficial" (p. 16). Parents saw their AD children's friendships as superficial because best friends often changed; the friendship was based around a few mutual interests with little indication of intimacy; best friends were sometimes 2-3 years younger than the AD child; and sometimes the best friend had only been seen by the child a few times (Church et al., 2000, p. 16). It seems that the parents in the Church et al. study were operating with a subjective definition of "best friend" that included the idea that a friendship should be long-lasting. The AD children in the Church et al. study seemed to have a variant subjective definition of what a best friend looked like.

All of the five high school aged AD males in the Church et al. (2000) study reported having at least one friend. As with the middle school students, the friendships of the AD boys were characterized as not being as deep as the friendships of their neurotypical classmates (Church et al., 2000, p. 18). "However, even though the relationships were characterized as more superficial than others, the boys themselves appeared to get out of these relationships what they wanted. It appeared that they did not desire a more in-depth friendship" (Church et al., 2000, p. 18). One possible limitation to the Church et al. study is that it seemed to rely more



heavily on the impressions of teachers and parents than on the impressions of the adolescents themselves.

When parent and teacher impressions were compared to child reports, it was found that AD children viewed their own friendships differently than their parents and teachers viewed those same friendships (Church et al., 2000). One resource documenting the experience of an AD child is the book *Freaks, Geeks & Asperger's Syndrome* written by Luke Jackson (2002), a 13-year-old British child diagnosed with Asperger's. Jackson (2002) offered practical advice to his readers, advising them to not stand close to others, not to follow peers around and not to incessantly talk about one topic if that topic is not "football, rugby or suchlike" (p. 164). In this passage, Jackson cleverly drew attention to the subjective nature of how ASD people are pathologized as having "encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus" (American Psychiatric Association, 2000, p. 77). What is considered pathological is often due to societal standards of what it is okay to be fixated on. Jackson pointed out that he doesn't understand why it is okay by societal standards to prattle on about football but not okay to be equally obsessed with computers. Robison (2011) made a similar point in his guidebook:

It was a sad day when I finally realized that most people do not care about the 66,000-horsepower MAN B & W diesel engines in the big American President Lines containerships. The world is just filled with important and fascinating facts, yet [neurotypical] people just choose to remain indifferent. (p. 55)

Jackson advised his readers to be selective in their friend making and not to change who they were to make friends. Jackson's opinions seem to be consistent with other ASD youth in that it is more important for him to select friends who are nice than these who are popular. Jackson wrote that having one reliable friend was good enough for him.

In addition to giving his readers advice on how to make friends, Jackson (2002) also stressed that it is not essential to have friends. He lamented that one teacher told him that it was time he got out there and "start having fun [as] if his idea of fun was the only way—yeah right!" (Jackson, 2002, p.165) Some of the Jackson's complaints agreed with the research showing that AD children have different views of what friendship looks like and how important it is.

Studies published in 2003 and 2006 examined friendship in Aspergian adolescents using the participants' own voices. Carrington et al. (2003) focused on the particular language that AD adolescents use when describing friendship and the importance of clinicians, teachers and other practitioners understanding this language. This study used interview questions that I will emulate in my study. Carrington et al. identified a few broad themes in his inductive data analysis: "(a) understanding of concepts or language regarding friendships (b) description of what is a friend, (c) description of what is not a friend (d) description of an acquaintance, and (e) using masquerading to cope with social deficits" (p. 212). Carrington et al.'s study found that participants were better able to identify characteristics of what is not a friend than what is a friend and that these characteristics included everything from not sharing interests to being untrustworthy, rude and stuck up (Carrington et al., 2003, p. 214).

Howard, Cohn and Orsmond (2006) conducted a case study on a 7<sup>th</sup> grade Aspergian male. Howard et al. (2006) found that friendship was important to the participant and that he had a strong desire to make and maintain friendships. This study found that family members played important roles in the establishment and maintaining of this Aspergian's friendships (Howard et al., 2006). The participant of the Howard et al. study was a 7<sup>th</sup> grade boy who was home schooled and attended tutoring and a social skills class with other Aspergian adolescents. Not

only did he have the desire for friendships, he also seemed to have at least one meaningful friendship. The findings of Howard et al. indicate that these extra supports may have positively influenced the participants' ability to make and maintain friendships.

Daniel and Billingsley (2010) conducted a study looking at how ASD adolescents established and maintained friendships. Consistent with Church et al. (2000) and Jackson (2002), Daniel and Billingsley found that the friendships of ASD boys were maintained through "sharing interests and engaging in mutually enjoyable activities" (p. 227). The subjects in the David and Billingsley study worried about forming friendships because they did not want to be the first person to initiate the friendship and because they did not understand the social hierarchy of the school and did not want to violate it.

Most of the research indicates that although AD children sometimes struggle to form friendships, they are able to make and maintain them. Friendships in AD children look differently than friendships in neurotypical children. While neurotypical children often find one or two best friends to have long-lasting relationships with, AD children may have shorter-lasting friendships. AD children often spend less time with their friends than neurotypical children. While neurotypical children seem to form intimate bonds with their friends, AD children often have friendships that revolve around seemingly superficial things like mutual interests. One striking difference is that while neurotypical children often strive to be friends with children they perceive as cool, AD children are more concerned with finding friends who not mean or too immersed in the social hierarchy.

While AD children may be perfectly satisfied with these friendships, parents and teachers sometimes see their friendships very differently. The research shows that parents and teachers of

AD children do not see their friendships as valuable because they do not look like neurotypical friendships. Forming and maintaining friendships are an important part of adolescence for both AD and neurotypical children. It is important that AD children and adolescents be given the freedom to determine what their friendships look like. Therefore, my research will look at what an AD friendship *does* look like without offering any pre-conceived definition.

### **Asperger's and School Friendships**

Daniel and Billingsley (2010) indicated that the most common place for ASD kids to make friends was at school because they felt uncomfortable making friends in other situations. This study contrasted with earlier studies, showing that ASD teens were able to maintain stable friendships for several years and through distances and transitions (Daniel and Billingsley 2010, p. 228).

Chamberlain, Kasari and Rotheram-Fuller (2007) conducted a study examining how 17 children with Asperger's and High-Functioning Autism functioned socially in regular-day 2<sup>nd</sup>-5<sup>th</sup> grade classrooms. Class involvement was determined in the Chamberlain et al. study using a centrality rating system, which showed how central to the social nucleus each child was thought to be. This study found that the children with ASD were less "centrally involved in the social structure of the classroom" than their neurotypical peers (Chamberlain et al., 2007, p. 235). However, none of the children in the Chamberlain et al. study were totally isolated from the social structure either.

Chamberlain et al. (2007) revealed the importance of parent and teacher involvement in ASD student achievement in a regular classroom environment. The child who had the greatest centrality rating of all of the ASD children in the study was a 2<sup>nd</sup> grade student whose mother

had worked closely with the girl, her teacher and the mother of a popular student to help her child become more socially involved in the classroom (Chamberlain et al., 2007, p. 237). The Chamberlain et al. study showed that although it is possible for ASD students to achieve in regular classrooms (especially with additional social supports), it is challenging and they often do not succeed on their own. However, it is important to note that AD children do not necessarily want to be part of the nucleus of the classroom and in fact, oftentimes actively avoid friendships with children they perceive as popular (Jackson, 2002; Carrington et al., 2003; Daniel & Billingsley, 2010).

In order to offer students with neurological differences a new kind of social environment, Kathryn Stewart, Ph.D. founded Orion Academy in 2000. Located in Moraga California, Orion Academy is the first college-prep high school for students with Asperger's Disorder. Stewart founded Orion Academy because it became clear to her that "adolescents with (Non-verbal learning disorder) and Asperger's Syndrome were in need of a more comprehensive program than the weekly outpatient treatment she was providing" ("Orion Academy Asperger's-NLD High School", 2010).

Orion Academy admits students with diagnoses of Asperger's and Nonverbal Learning Disability. Like Aspergians, students with NLD usually have a high level of verbal skills, with similar difficulties in processing information and engaging in social interaction (Stewart, 2007). The Orion Academy program "is designed as a safe learning environment with a specific focus on remediating motoric, social, emotional, and visual-spatial deficits ("Orion Academy Asperger's-NLD High School", 2010).

The small class size at Orion Academy allows children to get the individual attention they need from teachers and peers alike. Each student at Orion Academy has a laptop which is periodically inspected to ensure it is kept organized to school satisfaction. Instead of getting individual homework assignments to take home, students simply have to open the digital folder containing all of their class work and notes from the teacher. Each classroom at Orion Academy is equipped with state of the art audio and visual equipment so that students are kept visually stimulated. Students also spend the bulk of their time with a small cluster of the same students in order to bolster a feeling of community and help them to build social relationships.

Another unique and crucial element of Orion Academy is the social skills training. The 8<sup>th</sup> grade program at Orion Academy includes four days of social skills classes ("Orion Academy Asperger's-NLD High School", n.d.). The goal of the 8<sup>th</sup> grade social program is to build a class identity, a set of social norms and to practice dealing with increased social expectations ("Orion Academy Asperger's-NLD High School", n.d.). In 9<sup>th</sup> grade students are taught about eye contact and body language, reading others' emotions, engaging in conversations effectively, learning basic self-care techniques collectively through psycho-education (Stewart, 2007, Appendix E). In 12<sup>th</sup> grade, students learn about independent living, college searching, young adult issues and job searching skills (Stewart, 2007, Appendix E). Orion Academy also has a dog-training program which spans all five years. The dogs are used as a metaphor for human life and by training them; adolescents learn how they can train themselves to have the social skills necessary for adulthood ("Orion Academy Asperger's-NLD High School", n.d.). Working with dogs also teaches students how to communicate clearly and affectionately. In order to train the

dogs, students must "communicate in a strong clear tone; hold the dog's gaze; and stand tall despite (an)...urge to bow down" (Bloch, 2004, p. 28).

The many social and academic interventions provided by Orion Academy, teamed with a sense of community and belonging, create a very different secondary school experience than the one experienced by most AD children. Students at Orion Academy also have the experience of being surrounded by peers with the same or a similar diagnosis.

Research on Asperger's and friendship indicate that Aspergian children have more difficulty forming friendships than neurotypical children and also have friendships that are seen by teachers and parents as less intimate. I hope that by conducting a research study using the voices of young Aspergians, I will be able to capture the essence of what friendship looks like to an AD adolescent at a non-typical academic setting. My research question is the following: with these additional social and academic supports, how do children at Orion Academy experience and understand friendship? By surveying the 8<sup>th</sup>, 9<sup>th</sup> and 12<sup>th</sup> grade students, I hope to determine if Orion Academy has any impact on students' abilities to establish and maintain friendships. In the following chapter I will discuss my methodology for this research project.

## **CHAPTER III**

### **Methodology**

This research study explored the perceptions of friendship held by Aspergian adolescents who attend a specialized school for students with the same or a similar diagnosis. My research study also explored what impact this specific social environment has on how these adolescents' perceive the concepts surrounding friendship.

My research method was qualitative and exploratory in design. As shown in my literature review, I did not find any existing studies on this topic. Asperger's is a fairly new diagnosis that has recently come under speculation from the American Psychiatric Association. There does not appear to be any research on how Aspergian adolescents in a specialized school perceive and understand friendship. Given the lack of any data on this specific phenomenon, I chose to explore this topic by asking open-ended questions.

I employed an inductive methodology in this research and attempted to follow my research subjects with my lines of questioning. In inductive research, the researcher "begins with a set of observations, seeks patterns in those observations, and generates tentative conclusions from those patterns" (Rubin & Babbie, 2010). It was appropriate to use the inductive method to conduct this research study because of the unexplored nature of this topic.



## Sample

My sample consisted of adolescents with Asperger's being educated in a setting specialized for their needs. My study population consisted of 8<sup>th</sup>, 9<sup>th</sup> and 12<sup>th</sup> grade students attending Orion Academy. In order to do probability sampling, I would have had to obtain a list of every AD adolescent being educated in a specialized school and take a random sample from that list. Due to financial and time constraints that prevented a random sampling method, my sample was purposive in nature; meaning that I purposely collected data from students at Orion Academy, because these are the most appropriate select group of people to speak to regarding my topic.

I used convenience sampling to gather my research subjects. My goal with recruitment was to compare the views of younger students (8<sup>th</sup> and 9<sup>th</sup> grade) to the views of outgoing students (12<sup>th</sup> grade) in order to judge the impact that Orion Academy has on students' views of friendship. Not every student at Orion Academy has a diagnosis of Asperger's. In order to be admitted to Orion Academy, students must "have a primary diagnosis of a neurocognitive disorder by a respected clinician" ("Orion Academy Asperger's-NLD High School", n.d.). By the time students apply for admission to Orion Academy, many of them have acquired differential diagnoses from several different physicians because Asperger's is often misdiagnosed or difficult to identify (Corvin & Fitzgerald, 2001). My goal for recruiting students, therefore, was to recruit all 8<sup>th</sup>, 9<sup>th</sup> and 12<sup>th</sup> grade students at Orion Academy who had *ever* received a diagnosis of Asperger's and had never had that diagnosis ruled out in their clinical assessment. In order to get this information on students, I had to directly access student files.

Dr. Schlegelmilch submitted my Consent for Data Access form to all 8<sup>th</sup>, 9<sup>th</sup> and 12<sup>th</sup> grade parents (see Appendix A). I received twelve consent forms back and therefore gained access to these students' files. The student files I looked at contained varying and sometimes contradictory pieces of information including psychologist recommendations, psycho educational testing results, Individual Education Plans from public schools and other previous school records. Not every file contained all of these records, and different doctors had given some children contrasting diagnoses. All of the files contained a Parent Intake Questionnaire (see Appendix B). Parents filled out this questionnaire during the application process. Therefore, the 12<sup>th</sup> graders' Parent Intake Questionnaires were four-years old, while the 8<sup>th</sup> graders' forms were only one-year old. One question on the Parent Intake Questionnaire asked parents to indicate what diagnoses their child had been given:

4. Does your child have a diagnosis (by a licensed clinician) of?
- |  |  |
|--|--|
| <input type="checkbox"/> Nonverbal Learning Disorder | <input type="checkbox"/> Asperger's Syndrome           |
| <input type="checkbox"/> Attention Deficit Disorder  | <input type="checkbox"/> Obsessive Compulsive Disorder |
| <input type="checkbox"/> Tourette's Syndrome         | <input type="checkbox"/> PDD-NOS                       |
- Other: \_\_\_\_\_ (Appendix B, p. 1)

Each child had diagnoses from different clinicians and there was no way to verify how these diagnoses were made. Therefore, I based my inclusion criteria on the parent report of an Asperger's Syndrome diagnosis. If a parent reported Asperger's Syndrome on the above question, the child was considered eligible for my study, no matter what other diagnoses were reported.

Of the twelve children whose files I looked through, all four 8<sup>th</sup> grades qualified for the study on the basis of parent-reported diagnosis of Asperger's. Only two 9<sup>th</sup> graders and two 12<sup>th</sup> graders qualified for my study on the basis of parent-reported diagnosis of Asperger's. After I

submitted my findings to Dr. Schlegelmilch, he sent my second round of consent forms out to these eight families (see Appendix C; Appendix D). I received all of these consent forms back. My final sample consisted of eight participants.

Only one of my participants was female. All eight participants identified as white. Half of the participants attended private school before Orion Academy, one of which was a specialized school for children with learning disabilities. Of the participants who attended public school before Orion Academy, one was in a special education program and one was in an Asperger's inclusion program.

In addition to Asperger's, some parents also reported that their children had been given one or more of the following diagnoses: Nonverbal Learning Disorder, Attention Deficient Disorder, Major Depressive Disorder, Anxiety Disorder, and Obsessive Compulsive Disorder. One child was also given a diagnosis of Bipolar Disorder (later found to be erroneous). Fitzgerald and Corvin (2001) published a study showing that people with Asperger's can be misdiagnosed with Schizophrenia Spectrum Disorder, Pervasive Developmental Disorder Not Otherwise Specified, Attention-Deficit Disorder, Obsessive Compulsive Disorder, affective disorders like depression and Non-Verbal Learning Disorder. There is also research indicating that adolescents with Asperger's may be more likely to experience affective disorders characterized by anxiety and depression (Russell & Sufroff, 2005; Kuusikko et al., 2008; Shtayermann, 2008; White et al., 2009, Yeung, 2009;).

The Parent Intake Questionnaire (see Appendix B) also asked parents to rate how well their child established and maintained appropriate friendships before coming to Orion on a scale of one to five—one being "almost always" and five being "never". The average of these eight

scores was three, implying that before entering Orion Academy, study participants sometimes established and maintained appropriate friendships.

The participants ranged in age from 13 to 17 at the time I conducted the research. One of the 8<sup>th</sup> grade participants was 13 and three were 14 years old. One of the 9<sup>th</sup> grade participants was 14 and one was 15 years old. Both of the 12<sup>th</sup> grade participants were 17 years old. The mean age of participants was 14.75 years and the median was 14.

All of the participants in the study attended Orion Academy throughout their high school careers. Both the 8<sup>th</sup> and 9<sup>th</sup> graders in the study attended Orion Academy since the beginning of 8<sup>th</sup> grade. When the 12<sup>th</sup> graders began Orion Academy in 2007, there was no 8<sup>th</sup> grade program. The 12<sup>th</sup> graders in the sample began Orion Academy in 9<sup>th</sup> grade.

### **Data Collection**

Data collection took place in three small focus groups: one group was comprised of 8<sup>th</sup> grade students, one group was comprised of two 8<sup>th</sup> grade students and one 9<sup>th</sup> grade student and one group was comprised of 12<sup>th</sup> grade students. Carrington et al. (2003) found that there was a lack of depth to the interviews about friendship. By using focus groups, I hoped to rectify this in my study. Focus groups are successful in helping people self-disclose because they give people the impression that they are alike in some way and that makes them feel that it is permissible to open up more than they normally would (Krueger & Casey, 2000, p. 9). I hypothesized that using focus groups with AD adolescents who are already familiar with one another would increase their comfort level.

My data collection instrument was unstructured. I asked open-ended questions with some spontaneous inquiry. My prepared focus group questions (see Appendix E) were based in

part on those asked in the Carrington et al. (2003) study. I also allowed participants time at the end of the focus group to mention anything that was not covered. I asked follow-up questions as needed if participants seemed disengaged and clarifying questions if participants responded tangentially and I needed more information. I had to occasionally redirect my participants back to my questions when they started to tell lengthy stories unrelated to the subject matter of the focus group.

### **Informed Consent Procedure**

The first step in gathering a sample was to contact the Head Psychologist at Orion Academy, Andrew Schlegelmilch, Ph.D. Dr. Schlegelmilch and I agreed that I would recruit 8<sup>th</sup>, 9<sup>th</sup> and 12<sup>th</sup> grade students for my study. In order to gather diagnostic information about prospective participants, I had to have direct access to student files.

Parental consent is mandatory for anyone outside of Orion staff attempting to access student files at Orion Academy. Dr. Schlegelmilch sent out an introductory email to all 8<sup>th</sup>, 9<sup>th</sup> and 12<sup>th</sup> grade parents with my Consent for Data Access form attached (see Appendix A). There are currently 62 students attending Orion Academy, with 32 students in the grades I was sampling; eight 8<sup>th</sup> graders, fourteen 9<sup>th</sup> graders and ten 12<sup>th</sup> graders. Dr. Schlegelmilch sent out the Consent for Data Access form to these 32 families. I received a total of twelve consent forms back from parents (four from each grade level). My response rate from this initial Consent for Data Access was 37.5%.

When this step was complete, I spent several hours at Orion Academy looking at the student files of my twelve prospective participants. The student files were stored in a locked file cabinet behind the receptionists' desk in the main office. Removing four files at a time, I looked

through student files in a reserved room in a building adjacent to the main office. I took notes on students in a journal that will be stored in a secure place until my research is complete. After my research is complete, I will destroy the contents of this journal. I shredded notes on the four students who did not qualify for the study.

The next step in the informed consent process was to send out the consent forms to the parents whose children qualified for my research. I sent out two consent forms, one for students and one for parents (see Appendix C; Appendix D). Dr. Schlegelmilch sent out an email to these eight parents copying Dr. Stewart, the president of Orion Academy and myself. Dr. Schlegelmilch once again stated that participation in the research was completely voluntary. Dr. Schlegelmilch forwarded my second email to parents along with two informed consent forms: one for parents and one for participants. He then asked for these consent forms to be returned within two weeks of the day he sent them out. All of the informed consents were returned within this time frame.

Before the focus groups began, I sent out an email to parents of participants with the dates, times and location of their child's focus group (see Appendix F). I also reminded parents that pizza would be provided to study participants. My incentive for serving pizza was to increase participants' comfort in the space by engaging them in a social and familiar activity. I also wanted to thank my participants for their time. Although I asked participants to specify which pizza flavor they would prefer on their informed consent form, I knew I would not be able to accommodate all requests. Therefore, I encouraged parents to pack a lunch in case their child did not like the pizza flavor I brought to the focus group. A few parents wrote back to this email

stating that their children would be present at the focus group. Out of my eight participants, two did not like pizza but did enjoy the soda I brought to the group.

### **Risks of Participation**

Because of the personal nature of the subject matter, I warned participants on the informed consent (see Appendix C; Appendix D) that it was possible for them to become overwhelmed or hurt by the material discussed. I warned participants that participation in the focus group may make them recall painful memories from their past and/or potentially hurt by comments that their peers make about friendship.

However, measures were taken to prevent participants from becoming upset or triggered during the focus group. Before the focus groups began, participants signed a Confidentiality Agreement (see Appendix G). This agreement stated that participants would not repeat specific quotes from their peers, and would only discuss the group in general terms. I answered participants' questions about the Confidentiality Agreement before participants' signed the agreements. I also asked participants not to use specific names of classmates at Orion Academy. All participants agreed to these guidelines and respected them throughout the focus groups. I did not ask participants to refrain from using names of those not at Orion Academy and several names of students not currently at Orion Academy were mentioned during the focus groups. Although this could have posed a problem, none of the participants alluded to knowing any person mentioned by another participant.

Before the focus groups began, participants were also reminded that they were free to leave the focus group at any time should they become upset or overwhelmed. Participants were also given a list of mental health referrals (see Appendix G), including the names of the two

school psychologists, to refer to should they become upset. No participants asked to leave the focus groups.

One risk of this study is that parents may have felt pressured to have their children take part in this study. Although Dr. Schlegelmilch stated in his email to parents that participation was voluntary, parents might still have felt pressured to have their children participate. There was also a risk that participants did not themselves want to participate, but that they felt pressured into participation by their parents or by Dr. Schlegelmilch. In almost all cases, participants appeared to be either enthusiastic or at least willing to participate. However one participant became very upset when this person was reminded that it was the day of the scheduled focus group. The participant expressed to Dr. Schlegelmilch and myself that they did not want to participate that day because they were "sick of their classmates" and did not want to have to spend lunchtime with them. Once the participant calmed down, this person was able to express that he or she still wanted to participate in the study, just not with their same-grade classmates or direct peers. We were able to accommodate this student by placing this person in the focus group with students from another grade.

The 40-minute focus groups were held during lunchtime in a room adjacent to the cafeteria. All identifying information about these students was held in confidence which will be maintained. However, because of the small size of the school and the location of the focus groups, it was not possible to maintain confidentiality due to the fact that anyone could observe the students who entered the focus group room. However, in order to ensure utmost confidentiality, I did not disclose information about who participated in the study to anyone other than Dr. Schlegelmilch.



## **Benefits of Participation**

Participants seemed to benefit from the study by connecting with their classmates in a way they had not yet experienced. Participants also had the educational experience of learning about what focus groups are and how they function. Participants in this study will ultimately benefit their school by helping Orion Academy better understand them and their needs, in their own words. They also had the benefit of participating in the development of knowledge about adolescents with Asperger's.

An addition benefit was that participants were given pizza and soda. Not all participants took advantage of this. Participants were also given the opportunity to eat lunch in the company of others. For some participants, this seemed to be an additional bonus as they may have not eaten with others had the focus group not taken place. Some participants were also given the opportunity to meet and engage with schoolmates whom they had not engaged with previously.

## **Precautions Taken to Safeguard Confidentiality and Identifiable Information**

Participants' names only appear in writing on the informed consent forms. Informed consent forms will continue to be stored separately from the Flipvideo I used for this study. Participants' first names can be heard on videos of the focus groups. I will be the only person who watches videos and takes notes on the focus groups. The video recordings of the focus groups will be kept in a secure location for three years or until they are no longer needed. When they are no longer needed, they will be destroyed.

Notes taken about the focus groups do not contain participants' names. Participants were codified according to grade level. The first focus group contained only 8<sup>th</sup> graders. Participants in this focus group were codified 8.1, 8.2 and 8.3. The second focus group contained both 8<sup>th</sup>

and 9<sup>th</sup> grade participants and participants in this focus group were coded 9.1, 9.2 and 8.4. The third focus group contained only 12<sup>th</sup> grade participants and these participants were coded 12.1, and 12.2.

As another measure to ensure participant confidentiality I will avoid disclosing the gender of particular participants. This is especially important because I only had one female participant, and she is the only female student in her grade. In my Findings and Discussion chapters, I will use only male pronouns when quoting specific participants.

It was not possible to guarantee anonymity or confidentiality. Before the focus groups began, participants were asked to sign a confidentiality agreement. However, there was no guarantee that participants would not break this agreement and talk about what was said outside of the group. The limits of confidentiality were made clear before participation in the focus groups began. My research advisor, Mariko Ono, will have access to the data after identifying information is removed.

When presenting and publishing my research, I will state the name of the school where the research is taking place. I will discuss the results of the three focus groups without giving any specific demographic information about the participants. The only information I will include is whether participants were in 8<sup>th</sup>, 9<sup>th</sup> or 12<sup>th</sup> grade. This is the only demographic information that is relevant to my research. Illustrative vignettes and quoted comments from individual participants will be disguised as much as possible.

## **Data Analysis**

I imitated the methodology described in the Carrington et al. (2003) study and constructed concepts based on the themes that emerged from the groups. I utilized the grounded theory method to help me “seek to discover patterns and develop theories from the ground up” (Rubin & Babbies, 2010, p. 308).

Chapter Four will describe the findings of my research, and will be divided into sections based on themes that emerged from the research. I will then conclude by discussing the implications of my major findings and making recommendations for further research in this area in Chapter Five.

## **CHAPTER IV**

### **Findings**

As detailed in previous chapters, my research study explores how Aspergian adolescents perceive and understand friendship. My research focuses on how Orion Academy has shaped my participants' views of friendship. As discussed in the Methodology chapter, I conducted three focus groups comprised of 8<sup>th</sup>, 9<sup>th</sup> and 12<sup>th</sup> grade students at Orion Academy in February and March 2011 with a total of eight participants.

My findings are subdivided by grade level to show how Orion Academy may have influenced participants' understanding of friendship. Within the grade level categories, my findings are subdivided into (a) conceptualization of friendship (b) intimacy and closeness (c) bullies and people who are not friends and (d) friendship at Orion Academy. The 8<sup>th</sup> grade category also includes a fifth subdivision titled "fitting in."

Overall, participants described experiencing intimacy in their friendships. Participants showed insight about what made someone a friend, what made someone not a friend and what made someone a bully. Participants valued niceness and lack of meanness in their friendships. Many participants thought of friends as people to share activities with. Almost all participants shared experiences of not fitting in, being bullied, and feeling excluded or disliked.

Comparison between the views of 8<sup>th</sup>, 9<sup>th</sup> and 12<sup>th</sup> graders highlighted that participants' friendship quality had positively changed during their time attending Orion Academy. Twelfth grade participants provided more elaborate description of what qualities they liked and didn't like in people. Eighth grade participants outlined more simplified definitions of friends as

people who were nice and people who weren't their friends as people who were mean. My findings indicated that participants were able to think in more depth about what qualities they liked and didn't like in people because they were no longer experiencing bullying on a regular basis. Twelfth grade participants cited Orion Academy as partially responsible for the positive changes they saw in themselves. They cited social skills classes in particular as helping them to socialize better with peers and adults.

### **Eighth Grade Participants**

**Conceptualization of friendship.** Eighth grade participants valued niceness in their friendships. These participants also stressed the importance of friends not being mean or rude. Friends were described as people who were accepting of them. Participant 8.4 repeated a quote he thought summed up the definition of friendship: "a true friend is someone who takes you in when the rest of the world casts you out."

Beyond the theme of niceness, 8<sup>th</sup> grade participants did not offer much characterization of friends. Eighth grade participants seemed unsure about what exactly made people get along with one another. However, they acknowledged that there were indescribable characteristics which bonded friends. Participant 8.3 explained, "friends like each other's personalities."

Eighth grade participants stressed the importance of friends as people who could engage in activities with them. All four 8<sup>th</sup> grade participants liked to play video games with their friends. Three out of four 8<sup>th</sup> graders thought that playing video games was the most fun thing to do with friends. Participant 8.2 also enjoyed playing a particular board game with his friends. When asked if it would be as enjoyable to play video games with someone who wasn't a friend,

participants said that it wouldn't be as enjoyable, especially if the other person was competitive in a mean way.

Eighth grade participants liked to talk to their friends *about* certain subjects, rather than about their emotions or things going on in their lives. Participant 8.2 said that he enjoyed talking to his friends about video games. Participant 8.2 explained that he also liked to talk to friends about "stuff that is going on or stuff that I'm considering or stuff that I want to happen."

Eighth grade participants thought it was possible to be friends with people who were different than them. They defined "different than them" as referring to friends being interested in different activities. Participant 8.2 said that he could only imagine being friends with someone who was different than him if they could still find activities to engage in together. When it came to differences as well as to similarities, 8<sup>th</sup> graders primarily defined friends in terms of activities.

**Intimacy and closeness.** Eighth grade participants unilaterally explained that they did not talk about their feelings with their friends. Eighth grade male participants explained that boys never talked about their feelings. However, some 8<sup>th</sup> grade participants said that they felt they *could* talk about their feelings with their friends.

Although 8th grade participants did not confide in their friends about their feelings, they did seem to share intimacy with their friends in other ways. Participant 8.4 had kept the same best friend since kindergarten and several other 8<sup>th</sup> grade participants had kept friends since early elementary school. Another indicator of intimacy was that 8<sup>th</sup> graders thought it was important that friends be able to offer constructive criticism. When asked what first came to mind when I used the word "friendship", Participant 8.3 said that a friend was a person who could give you

advice. Participant 8.2 and 8.3 agreed that they wanted their friends to tell them when they were acting stupid or mean. Participant 8.1 disagreed, saying that it was not important to be criticized by friends.

Eighth grade participants also wanted to be able to trust their friends. They explained that a friend was a person they could rely on, and who would be there for them in good times as well as bad. Participant 8.4 thought that trust was the *most* important quality of a friendship.

Participant 8.2 described a situation in which he successfully confronted a good friend about a new friend he had made: "Then I told my friend, you know, this guy's kinda being a big jerk and then, after that he was not friends with him. I've been friends with him for awhile so he trusts me about stuff." Participant 8.2 was comfortable enough and cared enough about the friendship to confront and confide in his friend. The friend trusted him enough to take his advice. This level of trust and caring are indicative of intimacy.

**Bullies and people who are not friends.** Participant 8.4 explained that some of his classmates were not his friends because they did not share any of his interests. He also disliked a particular classmate who made sexist, racist and homophobic comments. With the exception of Participant 8.4, 8<sup>th</sup> grade participants tended to identify people they weren't friends with as enemies or bullies, rather than people they had little or nothing in common with. To 8<sup>th</sup> grade participants people tended to either be friends or enemies, there was little mention of people being acquaintances.

Some 8<sup>th</sup> graders described enemies as people who didn't like something about them. Participants 8.2 and 8.3 said that occasionally people thought they were jerks and therefore became their enemies. Participant 8.2 also suggested that someone might not like him because

they knew something bad about him. Participant 8.4 thought some people at his old school had scooted away from him when he sat down because they thought he was weird.

One 8<sup>th</sup> grade participant did not think that meanness was a fixed characteristic.

Participant 8.3 explained how someone who used to be mean could change:

I noticed that sometimes when people were really rude it was when we were really young, like in 1st grade, a person who called me names, he eventually matured and became nicer. A lot of kids were kinda mean but in 2nd grade. [Classmates] thought I was weird and they would talk about me and move away from me but then they got nice so I think they just needed to mature. But the girl in 3rd grade who kicked me with the soccer ball, she didn't get better.

Participant 8.3 went on to explain that the younger a person was when they were mean, the more likely they were to change.

Eighth graders spent significant time during the focus groups describing people who had been rude or mean to them. They seemed eager to compare and contrast their experiences of bullying. Participants mentioned the following examples: peers moving away from them, peers calling them names, peers pushing or otherwise physically injuring them, peers taking possessions or food from them and peers purposely getting them in trouble. Participant 8.2 shared his understanding of how and why he was bullied at his former school:

A lot of times when I would try to do something with the jock people they would do something annoying. If I was trying to go sit down on a bench they would always try to sit there. And they would always try to take my spoon so I couldn't have dessert. It got even worse because they were always name-calling if you're not good at sports. They would always get me in trouble by saying I did stuff, like hitting themselves and saying I did it.

Although 8<sup>th</sup> grade participants were angry about the bullying they had endured, they also showed sympathy for their bullies. Participant 8.4 reflected that a lot of the bullies had come from "bad situations at home." Participant 8.3 thought that his bullies hadn't meant to make him



feel bad. Participant 8.4 explained that one positive effect of being bullied was that now he wanted to grow up and help people to prevent them from becoming bullies.

**Not fitting in.** Not fitting in was a major theme for 8<sup>th</sup> grade participants that was not emphasized by other grade level participants. Eighth grade participants discussed not fitting in due to their style, their deficient social skills, their physical appearance and their lack of athleticism.

Participant 8.4 said that people had thought he was weird at his old school for dressing “goth” and having an awkward run. Participant 8.2 was un-athletic at a school where sports ability was highly valued. Participant 8.1 said that he didn’t fit in, but wasn’t specific about why this was. Participant 8.3 thought that most of the people at his old school were equally popular except for a few “outcasts.” Participant 8.3 then went on to explain that an incident at school had turned him into one of these outcasts:

At [my old school] I got branded a racist...by the whole entire school. First, let me put it into context. [This] school is a liberal school that goes out of its way sometimes to put down racism...I basically said, “Well, what about affirmative action?” I got told I was a racist and it all went downhill from there...After that any mumble under my breath got interpreted as “I hate Mexicans.”

Participant 8.4 explained that he had difficulty fitting in because he didn’t know how to socialize with peers:

My problem with socializing is that at my family events, like when we go to dinner at my relatives' house, all we do is tell weird stories but that's what I do with my friends and then it kind of bores them.

Several 8<sup>th</sup> grade participants said that they had purposely stayed out of the social hierarchy at their old schools. Participant 8.1 explained:

There was a very strange social hierarchy and there were four people who they all considered themselves on top of everyone else and the other people wouldn't care. And everyone started hating each other at a certain point, except for me. I didn't care.

Participant 8.1 later elaborated that he was happy not to be involved in the social hierarchy because the people on the top were always picking on one another. Some 8<sup>th</sup> grade participants implied that, in fact, they looked for friends who were also uninvolved in the social hierarchies of their schools. For some 8<sup>th</sup> grade participants, interest in popularity constituted a negative trait.

**Friendship at Orion Academy.** Participant 8.4 thought that it was easier to be friends with other people who were diagnosed with Asperger's and that it was hard for him to socialize with anyone who did not have Aspergers. Participant 8.4 seemed to think that this contributed to it being easier to have friends at Orion Academy.

Other 8<sup>th</sup> grade participants thought that Orion Academy students were easier to get along with because they weren't mean. Participant 8.2 explained that there were just a few people at his old school who were nice like Orion Academy students. Eighth grade participants said that it was easy to establish friendships when they came to Orion Academy, in part because some of them already knew each other and in part because people weren't mean to them.

Participant 8.4 thought that it might be easier to make and maintain friends at Orion Academy due to its small size: "It's a lot easier for me to socialize here because there are a lot less people. It was a lot harder to choose who I wanted to eat with at lunch [at my old school]." Eighth grade participants at first said there was no social hierarchy at Orion Academy. After discussing this, they determined that there was a social hierarchy but that it was manageable.

## **Ninth Grade Participants**

**Conceptualization of friendship.** Similar to 8<sup>th</sup> grade participants, both 9<sup>th</sup> grade participants said that they enjoyed playing video games with their friends. Ninth graders agreed with 8<sup>th</sup> graders that it was important that friends share their interests. Participant 9.1 said that his friends were also interested in animals and Participant 9.2 stressed that he liked playing paintball with his friends.

Similar to 8<sup>th</sup> graders, ninth graders thought friends were people who were accepting of them. Participant 9.2 explained that friends had to understand how hyper he sometimes got and had to be able to understand his inside jokes. Participant 9.2 described the process behind deciding if a friend was accepting: "I wouldn't ask them, well would you be okay with this. But in my head there is this thing going, hmm, I see them doing this, so that could mean that they don't do this."

Ninth grade participants also thought it was possible to be friends with people who were different than them. Ninth graders seemed to have more of an understanding of who their friends were beyond the activities they did. Participant 9.2 explained that one of his best friends was a Catholic Republican, while he was a Jewish Democrat. Although he recognized that this constituted a large difference between them, he explained that they were able to look past these differences and be close.

**Intimacy and closeness.** Both 9<sup>th</sup> grade participants reported that they had long term friendships. Participant 9.2 seemed to have several friendships which were deeper and more intimate than the friendships experienced by 8<sup>th</sup> grade participants. Participant 9.2 said that he acted differently around different people, but he liked how he acted around his friends.

Participant 9.2 relayed a story about knowing what a friend was thinking: "Sometimes when we are in the car together...we won't be saying anything but thoughts are going back between our heads." Later in the conversation Participant 9.2 said that the difference between friends and acquaintances is that friends you know "almost 100%."

**Bullies and people who are not friends.** Similar to 8<sup>th</sup> grade participants, 9<sup>th</sup> graders defined people who were not their friends as those who had bullied or been mean to them. Similar to Participant 8.4, Participant 9.2 defined racism as a quality that made them not like somebody. It seemed as though Participants 9.4 and 9.2 associated the quality of racism with bullying, perhaps because they saw racists as bullying others.

Like 8<sup>th</sup> graders, 9<sup>th</sup> grade participants did not think that meanness was a fixed quality but thought that it was possible for people to change for better or for worse. When asked about what came to mind when I mentioned 'friendship', Participant 9.2 stated the following:

I usually [don't think of people] that I used to be friendly with but that I don't like because of something they did. It changes over time because you may be friends with someone one day, and then they could have harmed you or did something you didn't like and then you might not be their friends that day.

Participant 9.2 reflected that a friend from his old school wasn't a good person to be friends with. He described how this ex-friend would beat people up if he didn't like what they did. Participant 9.2 now seemed to have enough distance from this former friend to be able to reflect that this probably had not been a very healthy friendship.

Participant 9.2 also thought people could change for the better. Participant 9.2 discussed having a friend who used to be really rude, but then eventually this friend matured, became nice and was now a good friend. Although Participant 9.2 thought it was possible for people to change, he said that if they were really bad, they never changed.

Ninth grade participants were also eager to discuss their experiences of being bullied prior to coming to Orion Academy. However, these participants were less specific about their experiences of bullying than 8<sup>th</sup> grade participants. Rather than giving details, 9<sup>th</sup> grade participants discussed how the bullying affected them and how they were able to recover from it. Developmentally, ninth graders are better able to summarize and use abstract thinking than 8<sup>th</sup> graders, and this seemed to be reflected in the answers given by participants. Participant 9.1 explained; "I was really looking forward to middle school...then this one kid ruined middle school for me because he didn't like me." Ninth grade participants also seemed to have perspective about what was behind the bullying. Participant 9.2 thought that bullies lacked self-confidence.

Participant 9.2 also showed insight about people pretending to be his friend. He said that although people at his old school thought they were tricking him, he knew all along that they were really just pretending to be his friend:

I didn't really consider them my friends though....because they would talk to you but you could tell there was something wrong with what they were saying...what they were saying was hinting at something which is what they meant but they weren't actually going to say. It's quite obvious, but they don't know that.

Participant 9.2 thought that bullying may have made him a stronger person and was also the impetus for getting him interested in his hobby: paintball.

**Friendship at Orion Academy.** Participant 9.1 explained that he was glad he had gone to Orion Academy because he thought things may have been more difficult for him at a public school: "[My brother] goes to a public school and from how he describes it, it sounds pretty cutthroat. Like, if you don't find a group to hang with within a week, you're dead." Participant 9.1 said that people at Orion Academy understood him.

Participant 9.2 explained that it had been easier for him to make friends at Orion Academy than at his old school. He thought that this may be due to people having similar diagnoses to him.

### **Twelfth Grade Participants**

**Conceptualization of friendship.** Twelfth grade participants were more descriptive than younger participants about what qualities they looked for in friends. Due in part to developmental differences, 12<sup>th</sup> graders showed more ability to conceptualize, use metaphors and verbalize their thoughts than younger participants. Twelfth grade participants defined friends as people they liked, not simply as people who were nice, or not mean to them. Twelfth graders seemed more secure than younger participants in their belief that others would like them, as demonstrated by their being in a position to decide who they did or did not like. Like younger participants, 12th grade participants thought it was important that friends share their interests. Participant 12.1 saw shared interests as being indicative of a deeper bond: "We share a similar church and so we share a similar goal in life...it is really close."

Like younger participants, Participant 12.1 thought it was important for friends to be nice and caring. While it was important to younger participants that a person be nice towards them, it was important to Participant 12.1 that a friend be nice and compassionate towards everyone—not just them. Participant 12.1 showed ability to generalize and place value on someone for being humane, not just for being nice to him. As Participant 12.1 explained, "it has been a long time since someone has been mean to me."

Unlike younger participants, twelfth grade participants named specific traits they looked for in friends. Participant 12.1 looked for friends who were smart, interesting and talkative.

Participant 12.1 also admired people who weren't as talkative as him, because this showed they were more deliberate about what they said. Participant 12.2 said that he liked down-to-earth people and that he did not like people who were too abstract or dreamy.

Unlike younger participants, who defined differences in friends as related to activities, interests and political beliefs, Participant 12.1 thought differences had more to do with attitudes and attributes. Participant 12.1 explained: "It's not like if someone [is smug or arrogant] I automatically don't like them. I am still capable of saying, well, this person still has some good qualities." However, unlike younger participants, Participant 12.1 thought that it would not be possible to be friends with someone who was too different.

Participant 12.2 began the focus group by saying that he did not enjoy spending time with other people. However, he later explained that he liked to spend time in chat rooms making and interacting with online friends. For this participant, face-to-face friendships may be too overwhelming. The Internet allowed him to make and maintain friendships in a more comfortable and non-threatening way.

**Intimacy and closeness.** Participant 12.1 explained that his friendships had evolved as he had gotten older: "As you mature your friendships mature. It can start out as a friend you talk about video games with but then it can turn into someone you spend a lot of time with outside of school." Similar to younger participants, Participant 12.1 said that he enjoyed playing video games with his friends. However he stressed that videogames were a backdrop for talking and enjoying one another's company:

One of my favorite activities with friends is talking...about whatever it [may] be. Sometimes we mix the two, talking while playing video games. But actually, one of the great things I have learned, I learned this recently, is going on bike rides. It's good exercise. Or walking and talking because, you know, when you are doing that you get

blood pumping to your brain. [We talk about] school, or random history stuff or video games, you name it!

Similar to younger participants, Participant 12.1 thought it was important to be able to rely on a friend. Unlike younger participants, Participant 12.1 did not just seem to be talking about reliance in the abstract. Rather, relying on his friends was something he had experience with.

Similar to younger participants, Participant 12.2 didn't think boys talked about their feelings. Participant 12.2 explained: "I'm un-reaching and unreachable. No one can make me talk about anything". Participant 12.1 was the only participant in any grade to say that he talked about his feelings with his friends:

I talk about my feelings with my friends. It depends on the context of course. If we are talking about video games I'm not going to suddenly say, "Oh I feel..." I will say to my really good friends, "I'm having a hard time lately" or "I feel kind of sad about this."

Participant 12.1 described the tight bonds he had with close friends as going beyond friendship. He explained that he was so close to some friends he thought of their bond as a *brotherhood* rather than a friendship:

With brotherhood, that's a really deep thing. That's reserved for people you can share absolutely anything with. And not only can you share anything with them, because you can share anything with friends, but you also don't feel uncomfortable sharing it with them.

**Bullies and people who are not friends.** Perhaps because 12th grade participants hadn't been bullied in several years, they seemed more able to think of other traits they didn't like in people. My findings indicated that 12<sup>th</sup> graders had developed the sense that they could actively choose their friends, because they no longer saw themselves in the passive or defensive stance of being the victim of bullying. My findings indicated that being bullied forced children to associate meanness with people who were not their friends. Twelfth graders, on the other hand, had the freedom to choose what qualities they did not value in people.



Both 12th grade participants agreed that they didn't like smugness or arrogance.

Participant 12.2 had a long list of things he didn't like: people who talked too much, people with annoying voices and people who were overly active. The two 12th grade participants disagreed about awkward silences. While Participant 12.2 said that he liked awkward silences, Participant 12.1 said they made him uncomfortable. Racism was also brought up in the 12<sup>th</sup> grade focus group. Participant 12.1 said that he didn't like people who were racist, and that racism was enough to disqualify someone from being his friend. Rather than considering the racist a bully, Participant 12.1 dismissed his views as ignorant. Participant 12.2 thought that everyone was a little racist and so this quality shouldn't disqualify someone from being a friend.

For the most part, the 12<sup>th</sup> grade participants viewed bullying as something that had taken place in the past. Although Participant 12.2 said that he was still occasionally called names at Orion Academy, he also said that he was bullied less at Orion Academy. Participant 12.2 shared that he had to leave a former school because of another student: "He pissed me off. He kept calling me stuff. He wouldn't leave me alone."

While younger participants discussed how others had changed from nice to mean and vice versa, Participant 12.1 discussed how maturing himself had impacted his desire to stay friends with someone:

One friend I had at Orion left two years ago. As I've matured a little bit I've begun to see that, "Oh gee, that person wasn't a good friend, now were they? Wow. He's kind of a real jerk, isn't he?" It's not that I made it apparent [to him], "Oh you're a jerk", I just don't make an effort to stay in contact.

When asked what could be done to prevent bullying, Participant 12.1 thought that the victim should do nothing because the bully would be the one to look foolish—not the person being bullied. While younger participants thought the only way to deal with bullying would be to go to

a teacher or other authority figure, Participant 12.1 thought that social peer pressure would deal with the bullying. He did not conceptualize an environment where bullying would be tolerated, not to mention encouraged. Participant 12.1's viewpoint on bullying is indicative of the kind of social environment he has learned to expect.

**Friendship at Orion Academy.** Participant 12.1 suggested that no one felt cast off at Orion Academy, and that this was a thing of the past for students. However, Participant 12.2 disagreed, saying: "I have been called a freak both here and at my old school."

However, later in the conversation, Participant 12.2 discussed how much better things were for him at Orion Academy than they had been at his old school. He identified lack of meanness as a positive trait of Orion Academy students and said, "Unlike at my old school, when I go up to people here, I'm not afraid they are going to kill me."

Participant 12.1 agreed with Participant 12.2 that there was a social hierarchy at Orion Academy. However he thought that other high schools were probably worse. Like 8<sup>th</sup> grade participants, Participant 12.1 thought that social hierarchy and cliques were a natural part of the teenage lifestyle. However, Participant 12.1 said that Orion Academy staff had tried to address the issue of cliques. Participant 12.1 admitted that he was part of the problem. He said that he only spent time with other 12<sup>th</sup> grade students and had kept the same close group of friends since he entered in 9th grade. Both 12<sup>th</sup> grade participants said that gossip occurred at Orion Academy. Both participants agreed that this gossip was "usually negative." Participant 12.2 lamented about being the victim of gossip. Participant 12.1 admitted to sometimes gossiping himself.

Both 12th grade participants felt that Orion Academy's social skills classes had helped them improve their abilities to make and maintain friends. Although Participant 12.1 and Participant 12.2 appeared to have very different personalities and very divergent views about the importance of friendship, both 12<sup>th</sup> grade participants thought that they had grown more able to develop and foster friendships as a direct result of Orion Academy's training.

Participant 12.2 began the focus group by stating that he did not like being around others. However, Participant 12.2 also discussed how this had altered slightly since being at Orion Academy. Participant 12.2 said that he had become "just a little bit" more of a people person since being at Orion Academy. He thought that he was a little better with people than he had been when he entered in 8<sup>th</sup> grade. Participant 12.2, who was psychically turned away from the table at the beginning of the focus group, added: "I guess now at school I don't really turn away from people as much." Participant 12.2 said that he wasn't sure what had caused this change but later in the conversation added that he thought the social skills classes may have helped.

Participant 12.1 also thought that Orion Academy had taught him social skills which had helped him get along better with people:

At first I would have problems understanding when is the right time to talk about something and when is not the right time. This is something Orion really helped me work on, well, both here and outside of Orion. Social Skills [class] has been a big help. In Social Skills we'll talk about things and they'll say: "Okay, you wouldn't want to say that around people" or "you shouldn't do this." That has been a real help because I'm not as socially adept as some people...When I go up to people now, I know how to properly introduce myself, as you saw. That's a very important technique, some people don't understand that. I think I have also learned very important things like you don't talk about certain things to someone you just met. There are appropriate things you can ask about someone you first meet like: "where are you from?" or "where do you go to school?" stuff like that, which is a very good skill. I didn't really understand that in middle school and to an extent when I first came here.

According to Participant 12.1, the social skills taught at Orion Academy have helped him to develop the skills necessary to socialize appropriately with others. He specified that social skills classes taught him that there are appropriate and inappropriate things to say to a stranger.

In his focus group, Participant 8.4 lamented that he had difficulties making friends because people became bored with the stories he told. Although Participant 8.4 saw his family telling stories, this same socializing strategy did not seem to work with peers. According to Participant 12.1's description, it seems possible that during the course of his career at Orion Academy, Participant 8.4 will learn that there are appropriate and inappropriate times to bring up certain topics. It is possible that this teachable skill will help Participant 8.4 make friends the way it helped Participant 8.4

The findings of this study indicated that older participants had deeper and more intimate understandings of friendship than younger participants. In the next chapter I will connect my findings to the literature and indicate strengths and limitations of my study. I will then discuss the implications of my study for practice and policy and will make recommendations for further research.

## **CHAPTER V**

### **Discussion**

This research study explored how Aspergian adolescents perceive and understand friendship. The focus of this research was on how participants' experiences at Orion Academy altered their understanding of friendship. I conducted three focus groups consisting of Aspergian 8<sup>th</sup>, 9<sup>th</sup> and 12<sup>th</sup> grade students to gather information regarding friendship.

As detailed in the previous Findings chapter, most of the participants experienced intimacy in their friendships on some level. Younger participants defined friends as people who were nice to them and enemies as people who were not. Twelfth graders tended to discuss bullying as something that had happened in the past. Unlike younger participants, 12<sup>th</sup> graders defined friends as people whose characteristics they liked. Eighth graders tended to think of friendship in more general and clichéd terms, while 12<sup>th</sup> graders showed a greater ability to describe real friendships they had had or wanted to have. My findings indicated that having some distance from bullying helped participants to think deeper about what qualities they liked and didn't like in people. Eighth and 9<sup>th</sup> grade participants thought that the smaller class size, the nicer students and the similar diagnoses of students enabled them to make friends at Orion Academy better than at their previous schools. Twelfth grade participants reported that friendship quality, social skills and self-esteem had positively changed during their time at Orion Academy. These participants attributed these changes to social skills learned at Orion Academy.

## **Comparison to the Literature**

My study found that AD children desire and value friendship. My participants also indicated that they understand when they are being rejected or bullied. Robison (2011) described his experiences of growing up as an Aspergian child before Asperger's was well understood. He reported that people would just assume he didn't know or care when he was being bullied or rejected (Robison, 2011). Since Robison was a child, research has shown that AD children do desire friendships and they understand when they are disliked by others. Bauminger and Kasari (2000) theorized that the existence of loneliness in ASD children showed that they had desire for friends and that they were hurt when they were rejected. All but one participant in my study discussed the desire to have friendships. Most participants in my study described situations in which they had been bullied or rejected. Many participants also understood that they were different than their peers and that these differences caused them to be teased or bullied.

Overall, participants in my study seemed to experience more intimacy in friendships than was indicated in the literature. Consistent with other studies of Aspergian adolescents, 8<sup>th</sup> and 9<sup>th</sup> grade participants in this study primarily identified friends as people who shared their interests (Church et al., 2003; Daniel & Billingsley, 2010; Howard et al., 2006). However, participants in this study also indicated that they had friends who didn't share their interests and that some friendships were also based on trust and understanding. Unlike the participants in the Church et al. (2000) study, my subjects had long-term friendships and were able to sustain friendships across geographic distance.

Church et al. (2000) gathered data from parents, teachers and psychologists and seemed to reveal more about how others viewed the friendships of AD children than about how AD

children, themselves, viewed their own friendships. In the Church et al. study, parents thought of their Aspergian children's friendships as superficial. This discrepancy between my data and this particular study's data may indicate that Aspergian children view their own friendships differently than how others view them. Participants in the Church et al. (2000) study also attended mainstream schools and interacted primarily with neurotypical peers, as opposed to the setting at Orion Academy. This may have impacted perceptions.

The Carrington et al. (2003) research also demonstrates this phenomenon in terms of the difference between Aspergian adolescents in mainstream vs. specialized schools. Carrington et al. interviewed Aspergian mainstream students ages 14-17 about their perceptions of friendship. The researchers found that participants were better able to name characteristics of people who were enemies or not-friends than people who were friends. The researchers also found an overall lack of depth to participants' responses, a phenomenon which was not present in my research. This may indicate that the structure of the focus group was more conducive to in-depth conversation, but also may indicate that children who attended a mainstream school did not have as intimate of friendships as participants in my study.

My data correlates with the data from the Carrington et al. (2003) study in terms of how participants separated individuals into categories: friends or people who were not their friends; they described these people as rude, inconsiderate, annoying and mean. This may indicate that AD children tend to see things in black and white terms, and it is difficult for them to see someone as not being a friend but not being an enemy. The prevalence of words such as mean, rude and annoying in both my study and in the Carrington et al. study indicates that AD children

may be more hypersensitive to these qualities, perhaps due to their proclivity to be bullied (Carter, 2009; Little, 2002) than other children.

Similar to participants in the Carrington et al. (2003) study, 8<sup>th</sup> and 9<sup>th</sup> grade participants in this study had an easier time describing characteristics they didn't like in people than characteristics they did like. Younger participants in my study seemed to be more familiar with the feeling of not liking someone than of liking them. Research shows that as many as 94% of Aspergian children and adolescents had been victimized by peers and siblings and two-thirds of AD children were victimized on an ongoing basis (Carter, 2009; Little, 2002). The discrepancy between participant's abilities to describe friends and people who were not friends indicates that both younger participants in my study and participants in the Carrington et al. study had more experiences of being bullied or teased than they did of having friends.

For instance, Carrington et al. (2003) described an 11<sup>th</sup> grader's impression of someone pretending to be his friend:

Jack described the mean and unfriendly behavior of some students who were not his friends. He stated, "They'll put me in a situation—like I say something and then they'll say, 'Ha! Just joking!'" (p. 214)

Jack's description of a fake friend was very similar to Participant 9.2's description of a fake friend from my study:

I didn't really consider them my friends though because they would talk to you but you could tell there was something wrong with what they were saying. What they were saying was hinting at something which is what they meant but they weren't actually going to say. It was quite obvious, but they didn't know that.

While Jack's description was given in the present tense, Participant 9.2's was given in the past tense because he was reflecting upon the bullying he experienced at his old school. In the anecdote, Participant 9.2 also placed himself in the triumphant position of being able to see



through the bully's plot. Comparison between the two anecdotes shows that Participant 9.2 has a more analytical view of bullying because he is no longer experiencing it firsthand, even though the participant from the Carrington study is two grades/years older developmentally.

Twelfth graders in my study did not discuss experiences of bullying like the ones Jack and Morris describe in Carrington et al. (2003). Rather, 12<sup>th</sup> graders discussed general qualities they liked and didn't like in people. Participants 12.1 and 12.2 were able to form detailed descriptions of who they would and wouldn't choose as friends. This may partially be because they are no longer basing their friend-making choices upon people being mean to them. They are also at a different place developmentally where they are able to be more thoughtful and critical about friendship.

Chamberlain et al. (2007) showed how a parent could help an ASD child form friendships. Chamberlain et al. conducted a study examining how 17 children with Asperger's and High-Functioning Autism functioned socially in mainstream 2<sup>nd</sup>-5<sup>th</sup> grade classrooms. The child who was rated the most socially involved was a 2<sup>nd</sup> grade student whose mother had worked closely with her child, the child's teacher and the mother of a popular student to help her child become more socially involved in the classroom (Chamberlain et al., 2007). Similar to Chamberlain et al.'s study, my study found that in an environment which supported them emotionally and socially, AD children were able to form meaningful and long-lasting bonds with other children. My study and the Chamberlain et al. study both showed that children could have active and involved social lives if they were given the proper support from collateral sources such as parents or teachers.

Although ASD children desire friendships, they often actively avoid friendships with children they perceive as popular (Carrington et al., 2003; Daniel and Billingsley, 2010; Jackson, 2002; Robison, 2011). Participants in my study also reported that they tended to avoid friendships with children who seemed overly involved with social hierarchy in peer groups. Participants seemed at times scornful of people who they thought were too interested in social climbing and seemed to prefer befriending people who were on the periphery of the social hierarchy.

Daniel and Billingsley (2010) indicated results similar to the findings in my study. Daniel and Billingsley conducted interviews about friendship with seven 4<sup>th</sup>-8<sup>th</sup> grade boys who attended mainstream schools. Out of those seven boys, only one reported not having friends. Similarly, out of the eight participants in my study, only one reported not having friends. Daniel and Billingsley also found that ASD children had maintained friendships through transitions and distance, which is reflected in my research as well. Both studies found that participants primarily formed friendships around mutually enjoyable activities. Participants in my study indicated experiencing intimacy, which was not experienced by participants of Daniel and Billingsley's study. This may be partially explained by the fact that the participants in my study were older. It also may be due to the difference in school environment. Daniel and Billingsley offer their understanding of how mainstream education affected participants' friendships:

Each of these boys has been included in general education settings throughout his school years. Their educational environments may have fostered friendships that are more similar to, rather than different from, the general population. Research comparing the friendships of youth with ASD from self-contained and inclusive programs may inform social and educational practice. (p. 227)

Howard et al. (2006) conducted a case study on a 7<sup>th</sup> grade boy with Asperger's whom they called Tom. Tom was home schooled and attended two weekly social groups with other

Aspergian adolescents. Similar to 12<sup>th</sup> grade participants in the current study, Tom valued certain qualities in his friends such as helpfulness, caring and support rather than defining friends simply as people who weren't mean or rude (Howard et al., 2006). Similar to the current study, Howard et al. found that an AD child who did not experience bullying, was exposed to children with similar diagnoses and who was taught social skills defined friends in descriptive and intimate ways.

### **Strengths**

This study accomplished the intended purpose of collecting information about friendship from participants in their own words. The major research question was the following: How do Aspergian adolescents attending a specialized school understand and perceive friendship? The research also looked at how perceptions of friendship may have been affected by time spent at Orion Academy.

My decision to use focus groups was inspired by the hypothesis that focus groups might encourage participants to give more in-depth answers than were generated from previous studies (Krueger & Casey, 2000). For example, in the Carrington et al. (2003) study, researchers interviewed participants individually and found that there was a general lack of depth in participants' answers. The use of focus groups as a collection instrument seemed to fulfill the desired effect. Some of the questions asked in the focus groups did not immediately resonate with participants. Usually only one or two participants would directly respond to a question. Those few participants would then share experiences that would inspire other participants to join the conversation. Oftentimes, after hearing a participant in their focus group share, group

members who formerly did not have anything to say about the topic would then chime in to agree or disagree with their fellow participants.

Using focus groups for data collection also helped to create group cohesion and a sense of safety and security that I could not have obtained by interviewing individual participants. Participants were familiar with one another before the group began and seemed fairly comfortable in the focus group space immediately, even though they did not know me. The open-ended nature of data collection was appropriate for answering my major research questions. Participants brought up topics in the focus groups that were not highlighted in the literature. The open-ended data collection tool allowed me to gather results that were not indicated in the literature.

Another strength of this study was that the participants were highly verbal and intelligent. Orion Academy only accepts students entering the 8<sup>th</sup> grade who “have above average of average verbal I.Q, as measured by a standardized assessment instrument [and] have a decoding reading level at or above the 8<sup>th</sup> grade level and a comprehension reading level at or above the 8<sup>th</sup> grade.” (“Orion Academy Asperger’s-NLD High School”, n.d.) Therefore, the participants in my study were likely more verbal, articulate, thoughtful and intelligent than an average group of eight Aspergian children. Participants therefore gave rich and detailed answers to many of the focus group questions and provided me with a wide array of excellent data on this topic.

### **Limitations**

One of the major challenges in my study was how *not* to make subjective interpretations of the data as the researcher. In defining terminology and interpreting how participants define concepts, I ultimately determined that the themes of trust, long-lasting friendships, confrontation

and knowing another person well all constituted intimacy. I also defined incidents experienced by students as acts of bullying. Interpretations like this are similar to the ones made by parents in the study by Carrington et al. (2003) who thought that their children's friendships were superficial. In my Findings chapter, I tried as often as possible to quote participants verbatim in order to voice participants' experiences without my own subjectivity. However, the subjectivity of me as the researcher is evident in the themes I chose as important and how I organized these themes. One limitation of this study is that my findings are highly influenced by subjective interpretations. The subjectivity of this study is linked to the nature of qualitative vs. quantitative data. Further research could be done on this topic from a quantitative perspective in order to reduce bias from subjectivity.

It is also important to note where my subjective opinion on this topic comes from. I have never been diagnosed with Asperger's Disorder nor do I have many of the traits associated with it. I am also not myself an adolescent. Therefore, I have approached this topic as an outsider and this no doubt effects my subjective interpretation of the data. Although I am not from the Bay Area, I do share much in common with the participants in this study because I am White, and was raised in an upper-middle class family in an affluent suburb. This perspective no doubt has affected my interpretation of the data, and also how the participants interacted with me as a researcher. Race was raised as a topic in all three focus groups, and would likely have been brought up differently had I not been perceived by participants as White.

A major limitation of this study was the small sample size. I used purposive, non-probability sampling. My sample consisted of only eight participants, while the suggested *N* for qualitative research is 12-15 participants (Rubin & Babbie, 2010). However, this sample was a

fairly accurate representation of Aspergian Orion Academy 8<sup>th</sup>, 9<sup>th</sup> and 12<sup>th</sup> grade students.

There are currently 62 students at Orion Academy and 32 students in the 8<sup>th</sup>, 9<sup>th</sup> and 12<sup>th</sup> grades.

My 8<sup>th</sup> grade sample was the strongest since four out of eight 8<sup>th</sup> graders (50%) participated in my research. Three out of 14 9<sup>th</sup> graders (21%) participated in my research. Three out of ten 12<sup>th</sup> (30%) graders participated.

Another limitation of the sample was that it was difficult for me to ascertain which students had a diagnosis of Asperger's and to reach out to them directly with consent forms. I only received half of the initial Consent to Access Data forms from parents. Unfortunately, I only allowed a week for parents to return consent forms and did not extend this deadline due to pressure from myself and the school to reach my original deadlines. If I had extended the deadline, I may have received a greater sample of consent forms and would have been able to look at a greater number of students' files. Half of the students whose files I looked at had a diagnosis of Asperger's. When I sent out the second round of consent forms to these families, I allowed families more time in which to return the forms. All of these second-round consent forms were returned. It was a limitation that I was not able to reach out with a second-round consent form to every child at Orion Academy who I knew had an Asperger's diagnosis.

I decided to run focus groups with 8<sup>th</sup>, 9<sup>th</sup> and 12<sup>th</sup> grade participants in order to compare the views of younger students to older students. However, looking back at this study, I would likely have garnered a larger sample had I reached out to 10<sup>th</sup> and 11<sup>th</sup> graders as well. It also would have been interesting to gather data from these participants to see the full trajectory of how friendship develops for students at Orion Academy.

My sample selection also lacked diversity and therefore is not generalizable to the broader population of Aspergian adolescents. While I did not obtain socioeconomic data about participants, it is reasonable to assume that all participants come from middle to upper class families due to some demographic data related to the school. All of the participants in my study lived in or around Moraga California, which as of the 2010 census had a median income of \$95,000 ("American Fact Finder", 2011). The 2010-2011 tuition for Orion Academy was \$29,775 ("Orion Academy-Asperger's-NLD High School", 2010). Roughly 50% of Orion Academy students have some or all of that tuition paid for through IEP's or scholarships ("Orion Academy-Asperger's NLD High School", n.d.) However, due to the cost of the school and the income level of the surrounding area, it is reasonable to assume that all eight participants come from middle or upper class families. Therefore, the sample used in this study does not represent the views and experiences of lower income Aspergian adolescents attending specialized schools. In fact, I found that there is a gap in the literature about the experiences of low-income Aspergian adolescents and this is a population which deserves further research.

Because my participants all identified as White, my sample was also not racially/ethnically diverse and therefore cannot be generalized to apply to the experiences of AD adolescents of color. However, this sample did represent the racial composition of Orion Academy students; almost all of whom are white. This sample also represents the racial composition of Moraga, which as of the 2010 census was 78% white ("American Fact Finder", 2011).

My sample was also not diverse in terms of gender. There is only one female 8<sup>th</sup> grader, four female 9<sup>th</sup> graders and two female 12<sup>th</sup> graders currently attending Orion Academy. Only

seven of the 32 (22%) of 8<sup>th</sup>, 9<sup>th</sup> and 12<sup>th</sup> grade students at Orion Academy are female. Only one of my eight participants (12%) was female. Statistically, Asperger's Disorder is more prevalent in males than in females: an estimated four males are diagnosed with Asperger's for every female (*DSM-IV-TR*, 2000). Some of the female participant's comments during the focus group appeared to be gender-specific. In order to protect her confidentiality, I did not specify gender when quoting particular participants. Friendship may be understood differently by male Aspergian adolescents than by females. Therefore, it is a limitation that my data was primarily collected from Aspergian males.

As stated earlier, all Orion Academy students have at least an average verbal I.Q., and grade-level comprehension reading levels (“Orion Academy Asperger’s-NLD High School”, n.d.) Therefore, none of the participants in my study had a less than average verbal I.Q or below average reading levels. Participants in this study were extremely articulate and highly verbal. Therefore, this study is not necessarily generalizable to Aspergian adolescents with below average I.Q.’s, below average reading levels, or learning disabilities or other concurrent diagnoses which make reading and I.Q. tests a challenge.

Due to feasibility, I gathered data from three distinct groups of 8<sup>th</sup>, 9<sup>th</sup> and 12<sup>th</sup> grade students rather than following the same participants throughout their Orion Academy careers. Gathering data from the same group of participants as they journeyed through Orion Academy would have allowed me to chart how individual participants’ understandings of friendship changed during their tenure. In the future, it would be useful to conduct a long-term longitudinal study at Orion Academy to investigate how individuals' perceptions changed over time.



In general, older participants showed a deeper understanding of friendship than younger participants. However, it is hard to decipher how much aging and maturity affected participants' perspectives and how much these perspectives were altered as a direct result of Orion Academy's interventions. Twelfth grade participants were also close to embarking on a major developmental milestone—graduating from high school. They were able to reflect on their experiences at Orion Academy with nostalgia, characteristic of graduating seniors at large. This nostalgia may have colored their anecdotes about Orion Academy. In order to determine how much participants changed their perspectives due directly to being at Orion Academy, it would be useful to conduct a comparison study of Aspergian adolescents at a mainstream school.

### **Implications**

The findings of this study imply that schools like Orion Academy help AD students to develop more in-depth understandings of how to make and maintain friends. According to study participants, it is easier to develop friendships at Orion due to a smaller class size, a less-ingrained social hierarchy, attending social skills classes, and being surrounded by students with similar diagnoses. All of these factors greatly contribute to Orion Academy students feeling safe and comfortable enough to determine whom they want to befriend, and then become friends with those people.

Twelfth grade participants cited social skills classes as being a key component in their abilities to get along better with others. As shown in the Findings chapter, one participant cited the social skills classes as helping him to make and maintain friendships, while the other 12<sup>th</sup> grade participant cited those classes as helping him to be less introverted and to reach out more to his peers. As discussed in the Review of the Literature, Orion Academy students attend social

skills classes throughout all five years. Eighth and 9th graders learn how to use eye contact and body language to understand others' emotions and engage in effective conversations. Eleventh and 12th graders learn about independent living, college searching, young adult issues and job searching skills. Orion Academy students also engage in a five-year dog obedience training program, where they work on empathy, master skills such as speaking in a stern voice and maintaining good body posture. ("Orion Academy Asperger's—NLD High School", n.d.) According to 12<sup>th</sup> grade participants some of the most important things taught by social skills courses were: how to introduce themselves; what topics were appropriate and inappropriate to talk about when; how to sit and engage with others; how to shake hands and how to maintain eye contact.

Orion Academy is able to provide these social skills courses, dog-training classes and other amenities in part due to the yearly cost paid by at least half of families: \$29,775 ("Orion Academy-Asperger's-NLD High School", 2010). This cost is preventive for most families with an Aspergian adolescent. However, one implication of this study is that students in mainstream schools could benefit from some of the programs provided to Orion Academy students. Instituting some of the Orion Academy social skills programming at mainstream schools could help Aspergian adolescents to make and maintain friendships. It may not be feasible for mainstream schools to provide social skills courses only for Aspergian students. However, research shows that an average of one in 110 children in the United States has an Autism Spectrum Disorder (Rice, 2006). Providing district-wide social skills courses for AD children may help to increase friend-building and maintaining skills; thus causing these students to have fewer issues with anxiety, depression and loneliness.

This study indicated that not being bullied at Orion Academy helped participants to develop more selective criteria for finding friends. For some participants these skills helped with the development of more meaningful and intimate relationships with people they liked. The issue of bullying recently regained national spotlight due to last year's suicide of a Massachusetts high school student, and the subsequent felony charges brought against six students who allegedly bullied her (Eckholm & Zezima, 2010). Although that victim did not have an Asperger's diagnosis, research shows that two-thirds of Aspergian children are victimized by their peers (Carter, 2009) and that half of Aspergian children have high levels of suicidal ideation (Shtayermman 2007; 2008). Therefore, Aspergian children at mainstream schools may positively benefit from anti-bullying programming and legislation. Views of Aspergian children and adults should be included in the national discussion about bullying and in the creation of anti-bullying programs. Participants in my study gave each other concrete advice about how to deal with bullies. Similarly, schools could provide space for AD children to advise one another about how to deal with bullying.

Participants also indicated that they found it easier to make friends with people who had the same or similar diagnoses. As one 9<sup>th</sup> grade participant explained, "people at Orion Academy understand me." The traditional special education model often recommends individual counseling for Aspergian students. While this is certainly helpful; especially around the co-morbid diagnoses of anxiety and depression; it might also be helpful for students to be placed in group therapy with other Aspergian students. During the focus groups for this research project, participants seemed delighted and relieved to find that their peers had experienced similar challenges with making friendships. It might be helpful for Aspergian children in mainstream

schools to learn that there are others who have many of the same challenges and talents that they do as a result of their unique brains.

Many of the participants in my study seemed to be aware of their diagnosis of Asperger's, regarded it very matter-of-factly and spoke about it without embarrassment or feelings of judgment. Parents, teachers and counselors are often worried about talking to children about Asperger's, due to possible stigma around the diagnosis. However, participants in this research seemed to view their diagnoses as just another thing that made them different or special. One ninth grade participant explained that there was "no such thing as normal." Participants in this study regarded themselves as weird, as different, or even as "freaks". However, they did not seem ashamed of this, but rather embraced it. One implication of this study is that talking to children about Asperger's may help them to understand the way their brain functions and may help them to feel—if not normal—than happy with their own abnormality.

This study helps to inform the understanding of Aspergian adolescents in clinical social work practice. The implications of this study are that clinical social workers could collaborate with AD adolescents to help them form more intimate and long-lasting friendships. It is clear that AD adolescents have both the desire and the ability to form these friendships. Social workers could help AD adolescents make these friendships by teaching concrete social skills, working with AD adolescents in groups as well as individual therapy, and working with parents around pragmatic discussions about the diagnosis of Asperger's. Social workers could also work with teachers and parents to decrease bullying in school settings for AD and neurotypical children alike. Social workers could also help educate parents and teachers about the diagnosis of

Asperger's, and can stress that although they may not verbalize it—AD children often know when they are being rejected and may feel this rejection very deeply.

## **Conclusion**

Graduates of Orion Academy will likely experience challenges in college, in the workforce and in their social lives not experienced by their neurotypical peers. Differences in the Aspergian brain make blending in to a world designed for neurotypical people a daily struggle. However, 12<sup>th</sup> grade participants felt that they knew how to get along with people better now than they had when they entered Orion Academy five years prior. For one 12<sup>th</sup> grade participant, this meant being able to form close bonds with several friends. For another participant it simply meant not turning away from people when they spoke to him. But both participants cited the programming at Orion Academy as causing these changes.

During the sensitive, terrifying and exhilarating life stage which is adolescence, Orion Academy provides a holding environment. Students are placed in an environment where they have less opportunity to fail because they are given every chance to succeed. Students are provided with structure, organization and a small, manageable cohort of peers who allow them to be themselves. Without the persecution of bullies, students are able to develop their own interests and make meaningful, intimate friendships with like-minded peers. In the unique environment of Orion Academy, it seems that Aspergian adolescents are able to develop and foster the kind of friendships they desire. Every AD child has the potential to form the kinds of friendships they want. With the proper support, every Aspergian adolescent can have those friendships.

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## **Appendix A**

### **Consent for Data Access**

Dear Orion Academy Family Member,

My name is Michelle Kaye and I am a 2<sup>nd</sup> year MSW student at Smith School of Social Work. In partial completion of my Master's, I am conducting a research study at Orion Academy. My topic of interest is the perceptions that 8<sup>th</sup>, 9<sup>th</sup> and 12<sup>th</sup> grade students at Orion Academy with Asperger's have of friendship. In order to determine which students qualify for participation, I must assess data on students. With your permission, I will review the neuropsychological evaluation submitted to Orion Academy when your child applied. If your child qualifies for the study by meeting the criteria for Asperger's, I will be reaching out to you again to get your consent for their participation.

Your signature below gives me permission to assess school files on your child. Please feel free to contact me directly with any questions. Thanks in advance for your assistance with social work research!

Kind Regards,

Michelle Kaye, MSW student

## Appendix B

### Parent Intake Questionnaire

*To be completed by parent or guardian and included in application to Orion Academy*

Today's Date: \_\_\_\_/\_\_\_\_/\_\_\_\_ Applying for the 200\_\_-200\_\_ academic year  
Name of Student: \_\_\_\_\_ DOB: \_\_\_\_/\_\_\_\_/\_\_\_\_  
Parent/Guardian: Student lives with \_\_\_\_\_  
Name: \_\_\_\_\_ (mother)  
\_\_\_\_\_ (father)  
Address: \_\_\_\_\_ (Street, City) (State, Zip)  
E-Mail Address (Required information) \_\_\_\_\_  
Home Phone: \_\_\_\_\_ Work \_\_\_\_\_ Cell: \_\_\_\_\_  
Medical Doctor: \_\_\_\_\_ Phone: \_\_\_\_\_  
Current medications: None \_\_\_\_\_ See list below \_\_\_\_\_

#### Education

1. Has your child ever been placed in a special education class? YES NO If yes, please describe:  
2. Date of last IEP: \_\_\_\_/\_\_\_\_/\_\_\_\_ District: \_\_\_\_\_ \* Include the most current IEP with this application

Office Use Only:

Date Rec'd \_\_\_\_\_

Reviewed by:  
\_\_\_\_\_

3. Does your student receive other services, either from the school or privately: Currently In the past?

Speech and Language \_\_\_\_\_ Occupational therapy \_\_\_\_\_ Counseling \_\_\_\_\_

Social Skills Group \_\_\_\_\_ Other: \_\_\_\_\_

4. Does your child have a diagnosis ( by a licensed clinician) of:

\_\_\_ Nonverbal Learning Disorder \_\_\_ Asperger's Syndrome \_\_\_ Attention Deficit Disorder

\_\_\_ Obsessive Compulsive Disorder \_\_\_ Tourette's Syndrome \_\_\_ PDD-NOS Other: \_\_\_

5. Has your student ever been held back a grade? YES NO Grade? \_\_\_\_\_

6. Has your student ever been treated for Behavior Problems – specifically, has a Behavior Intervention Plan (BIP) ever been implemented by his/her school ?

YES NO

If yes, please explain  
\_\_\_\_\_

7. Was there a time when your student really disliked school? Yes No

Please explain  
\_\_\_\_\_

8. For grades 6-8 (or any high school classes), was your student's school performance on the whole below average, average or above average in the following

Math \_\_\_\_\_ Reading/decoding \_\_\_\_\_ Writing \_\_\_\_\_ Vocabulary \_\_\_\_\_  
\_\_\_\_\_ Handwriting \_\_\_\_\_ Reading Comprehension \_\_\_\_\_  
Physical education \_\_\_\_\_ Music/Arts \_\_\_\_\_ Science \_\_\_\_\_ History \_\_\_\_\_

9. Why are you applying to Orion and whose idea was it to come?

### Other Information

10. Household members: (Who lives in the students home?)

Name Relationship Age

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11. If the student lives in a second household, please describe the arrangement and who lives there:

12. Has your student ever had psychological or neuropsychological testing? YES NO If yes, please list & include testing that is within the past 5 years Date Clinician Reason/who requested

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13. Has this student ever been in therapy before? YES NO When and with whom?

### Peer Relations

Does your student have close friends? YES NO

If yes, do they see each other regularly outside of school or other organized setting?

No Yes – How often \_\_\_\_\_

Who does your student socialize with regularly?

Mainly boys \_\_\_\_\_ girls \_\_\_\_\_ both \_\_\_\_\_ neither \_\_\_\_\_

Mainly older \_\_\_\_\_ younger \_\_\_\_\_ adults \_\_\_\_\_ same age \_\_\_\_\_

How does this student generally get along with peers? Please describe

Is this student teased by others? YES NO

If yes, please describe

Is this student the instigator of problems with others at school YES NO

Is this student the instigator of problems with others at home? YES NO

Please describe

Does this student have a pet? YES NO

What kind? \_\_\_\_\_

### Clinical Information

Please have parent and student fill this out together – if you disagree, use a different color pen to score separately

Using the following scale, answer each question as it pertains to your student.

0= none or never

- 1= 1-2 times in past (over 6 months ago)
- 2= a few times/month
- 3= 1-3 times/week
- 4= daily or almost daily

0 1 2 3 4

- Worries about harm happening to someone in the family
- Worries about being separated from parent or other person student is with
- Easily upset about being alone
- Nightmares
- Refuses to go to school OR has frequent physical complaints and asks to stay home
- Worries about doing things right, needs to know EXACTLY how to do something
- Becomes upset with a change in routines
- Has anxiety symptoms (difficulty breathing, heart pounding, sweating, dizziness, faintness, etc)
- Fails to finish things started
- Easily distracted/ Difficulty concentrating
- Has trouble getting started on tasks
- Seems not to listen to parent or teacher
- Difficulty sticking to activities – play/recreation

0 1 2 3 4

- Difficulty following verbal instructions
- Difficulty following written instructions
- Has trouble organizing work
- Need a lot of supervision
- Frequently blurts out in class
- Has difficulty waiting for help or attention
- Overly active
- Talks excessively
- Fidgets, has trouble sitting still
- Has trouble falling asleep
- Has trouble staying asleep (awakens early)
- Snoring
- Sleepwalks
- Bumps into things, is clumsy

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Please answer the following YES or NO questions regarding your student. Feel free to add information on additional sheets if you feel it will help us understand your students and evaluate the appropriateness of this placement.

Has your student ever been diagnosed with the following?

Muscle tic YES \_\_\_\_\_ NO \_\_\_\_\_ When \_\_\_\_\_

Vocal tic YES \_\_\_\_\_ NO \_\_\_\_\_ When \_\_\_\_\_

Depression YES \_\_\_\_\_ NO \_\_\_\_\_ When \_\_\_\_\_

Drug addition or drug dependence YES \_\_\_\_\_ NO \_\_\_\_\_ When \_\_\_\_\_

Bipolar Disorder YES \_\_\_\_\_ NO \_\_\_\_\_ When \_\_\_\_\_  
Medical Condition (Please list) YES \_\_\_\_\_ NO \_\_\_\_\_ When \_\_\_\_\_

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Has your student ever attempted suicide YES \_\_\_\_\_ NO \_\_\_\_\_

If yes, please describe – use a separate sheet if necessary

Has your student had a serious tantrum lasting more than half an hour?

YES \_\_\_\_\_ NO \_\_\_\_\_

If yes, Please describe when and under what circumstances – use another sheet if necessary

What is your student's USUAL mood?

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Has this students ever had trouble learning motor tasks – (such as, tying a shoe, riding a bike, handwriting) YES \_\_\_\_\_ NO \_\_\_\_\_

Has your student ever been evaluated for Occupational Therapy? YES \_\_\_\_\_ NO \_\_\_\_\_

If yes, has he/she received services YES \_\_\_\_\_ NO \_\_\_\_\_ When? \_\_\_\_\_

Does your student have any extreme fears or phobias? YES \_\_\_\_\_ NO \_\_\_\_\_

If yes, please describe

If there is anything else you feel we should know about your student that has not been covered here, please describe

Name of person completing this form:

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## Appendix C

### Parent Consent Form

Dear Family Member of Participant,

Thank you for giving me consent to look at your student's file. Your child has qualified to participate in my research study! Once again, my name is Michelle Kaye and I am a student at Smith School of Social Work. For my MSW thesis, I am doing a research project on friendship in Aspergian adolescents. The purpose of this research is to learn more about what friendship is like for 8<sup>th</sup>-12<sup>th</sup> grade students with this diagnosis.

Participants will take part in a 30-minute focus group. Filling out the confidentiality form, consent form, going over safety issues and traveling to and from the group will likely take an additional 30 minutes. There will be 5-10 participants per focus group. Focus groups will be semi-structured and will be conducted by me during your child's lunch. The interviews will be recorded using an audio device and then will be transcribed by me on my personal computer. Participants must be current Orion Academy High School Students in the 8<sup>th</sup>, 9<sup>th</sup> or 12<sup>th</sup> grade. Your child must have been given a diagnosis of Asperger's at some point in their lives.

There are no foreseen risks to participants. However, before the focus group begins, participants will be told that they are free to leave should they become overwhelmed at any point. A list of mental health referrals will be given to participants before the group begins. A potential benefit to participants is getting the opportunity to vent about their negative experiences and getting to connect with their classmates in a different way. Your child will be given pizza as an extra incentive to participate.

The focus group materials will be kept confidential and names of participants will not be shared with anyone. The school will make its best effort to ensure that the focus groups are conducted in a private space free from interruption. Participants will be asked to sign a Confidentiality Agreement before their focus group begins. However, there is no way to guarantee that participants will keep the confidentiality agreement. Participants will be made aware of this. After the data is collected it will be kept in a secure location for three years as federally mandated. Should material be needed after three years, it will continue to be kept in a secure location and destroyed when no longer needed. When the research is presented, all identifying information will be carefully disguised. Participation in this study is completely voluntary. Participants may withdraw from the study at any time during data collection and may refuse to answer any question. Should participants choose to withdraw, it is not possible to destroy the data related to them as this would effect the rest of the data from that focus group. Your child can withdraw from this study by contacting me by email, by phone or in person. Should you have any concerns about your child's rights or about any aspect of the study, you can call me or the Chair of the Smith College School for Social Work Human Subjects Review Committee at (413) 585-7974.

**YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR CHILD'S PARTICIPATION, AND YOUR CHILD'S RIGHTS AND THAT YOU AGREE TO LET YOUR CHILD PARTICIPATE IN THIS STUDY.**

## Appendix D

### Participant Consent Form

#### **You are invited to a Focus Group Pizza Party!**

Dear Participant,

Hello! My name is Michelle Kaye and I am a graduate student at Smith School of Social Work. I am doing a research project on friendship in 8<sup>th</sup>, 9<sup>th</sup> and 12<sup>th</sup> grade Orion Academy students with Asperger's.

If you choose to be in my study, you will take part in a 30-minute focus group. Traveling and paperwork will likely take another 20 minutes of your time. Your focus group will take place during lunch. I will record focus groups and store the information on my computer.

There are no risks to participation. However, should you become overwhelmed or upset, you are free to leave the focus group. You will also be given a list of mental health referrals at the focus group before it begins. A potential benefit is getting the opportunity to vent about your negative experiences and getting to connect with their classmates in a different way. Pizza will be provided as an incentive to participate!

The focus group materials will be kept confidential and your name will not be shared with anyone. Focus groups will be conducted in a private space. You will be asked to sign a Confidentiality Agreement before the focus group begins. However, there is no way to guarantee that participants will keep the confidentiality agreement. After the data is collected it will be kept in a secure location for three years as federally mandated. Should material be needed after three years, it will continue to be kept in a secure location and destroyed when no longer needed. When the research is presented, all identifying information will be carefully disguised.

You only have to participant in this study if you want to and you may withdraw from the study at any time during or before the focus group. You cannot withdraw from the study after the focus group has taken place. If you have questions, you can call or email me.

**YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THIS STUDY.**

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Pizza preference: \_\_\_\_\_



## **Appendix E**

### **Focus Group Questions**

1. What comes to mind when I say the word 'friendship'?
2. What makes someone a friend?
3. What makes someone an acquaintance?
4. What makes someone "not a friend"?
5. What things are enjoyable and work well about your friendships?
6. What sorts of things are difficult about your friendships?

## **Appendix F**

### **Email Reminder to Parents**

Dear Parent,

Thank you for your interest in my research study! I am very excited to meet and hear from your child. If you are interested in this study and have not yet returned your consent forms, please return them to Dr. Schlegelmilch before the 14th if at all possible.

All focus groups will take place at Orion Academy during lunch, beginning at 12:30. The 8th grade focus group will take place February 15th. The 9th grade group will take place February 16th. The 12th grade group will take place on February 28th. Your child will be provided with pizza and an effort will be made to follow their request. However, I do recommend that they be given something to eat on the day of their focus group in case I am not able to accommodate everyone's wishes.

Thanks again for all of your help and participation. Please feel free to contact me directly with questions or comments.

Michelle Kaye, MSW student

## **Appendix G**

### **Confidentiality Agreement**

I \_\_\_\_\_, agree to keep what is said within the group confidential. When speaking about the group to my peers, family members and others, I will not repeat specific quotes from other participants. I may speak about general trends in the group but I will not repeat what specific members said. I will not use participants' names when talking about the group. I will keep the names of fellow participants as private as possible. When talking to my fellow participants about the focus group after the group takes place, I will speak in a private area so I am not overheard. If I am speaking in a public area I will be as vague as possible and will not repeat specific statements or names.

Signed: \_\_\_\_\_ Date: \_\_\_\_\_

## **Appendix H**

### **Mental Health Referrals**

#### **At school**

Dr. Schlegelmilch, Ph.D.

Stephanie Crampton, Psy.D.

#### **Moraga/East Bay**

Cynthia Brody, MFT: (925) 926-6566

John D. Mason: (925) 308-5962

Tim Tisdell, Ph.D. (510) 339-8221

#### **San Francisco**

Elizabeth Ehrenberg, MSW: 415-828-4563

Dr. Sarah Villarreal, PsyD: (650) 268-9787 x2

Stephen D. Karr, Ph.D., ABPP Director of San Francisco Institute for Adolescence:

(415) 221-1952

## Appendix I

### Human Subjects Review Approval Letter



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Smith College  
Northampton, Massachusetts 01063  
T (413) 585-7950  
F (413) 585-7994

December 8, 2010

Michelle Kaye

Dear Michelle,

Your second revisions have been reviewed. I guess we'll have to go with Dr. Schlegelmilch. I don't think you could get away with this with the average kid who would be curious, maybe teasing, having all kinds of ideas and buzzing about why the group disappeared etc. And the participants would be very self-conscious. But he knows these kids and the setting and is reassuring. We therefore are now able to approve your interesting study.

*Please note the following requirements:*

**Consent Maintaining Data:** You must retain all data and other documents for at least three (3) years past completion of the research activity.

*In addition, these requirements may also be applicable:*

**Amendments:** If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

**Renewal:** You are required to apply for renewal of approval every year for as long as the study is active.

**Completion:** You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

I wonder if the way Dr. S. predicts the kids will handle this is connected to the possibility that they have less intense interest in others.

This is a very useful topic. It will be fascinating to see how these kids manage the focus group. Good luck with your project.

Sincerely,

A handwritten signature in cursive script that reads 'Ann Hartman' followed by a flourish.

Ann Hartman, D.S.W.  
Chair, Human Subjects Review Committee

CC: Mariko Ono, Research Advisor