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# Parental Satisfaction and Teacher Perspectives on Inclusive Education of Students with Asperger Syndrome: An Educational Tool

by

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Bachelor of Arts Clemson University, 2012

Submitted in Partial Fulfillment of the Requirements

For the Degree of Master of Science in

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School of Medicine

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## **Dedication**

For my family, who has unconditionally been in my corner since Day 1.

## Acknowledgements

I would like to thank every teacher, professor, coach, and classmate from kindergarten until now who has had a part in shaping not only my education, but also the person I am today. I would like to especially thank everyone involved in the USC Genetic Counseling Program – I could not have ended up at a more perfect place to achieve my dream career. To my classmates, who have become seven of my closest friends, to Janice, who has always been our #1 supporter, and especially to Peggy, without which this thesis would not have flourished.

I would also like to thank Debbie for believing in my ideas, and all of the parents and teachers who respected this topic and my abilities enough to participate in our research. The autism community is one of the most supportive groups I have ever had the pleasure of being involved with, and I will enjoy carrying this relationship into the future. Last but certainly not least, I would like to thank Dr. Ferrante, who always made sure I was cool, calm, and collected. Go Tigers, and Go Blue Devils (except during basketball season).

#### **Abstract**

**Purpose:** This study aimed to evaluate parental satisfaction and anxiety regarding the high school educational experiences of their child with a previous diagnosis of Asperger syndrome (AS), as well as educators' understanding of the diagnosis and what information they deemed important to know about the student. The goal of this study was to develop an educational tool that would aid in initiating communication between parents of a student with AS, or with a new diagnosis of high-functioning autism (HFA), and their teachers. This would be an additional resource of use to pediatric genetic counselors that frequently see families regarding a diagnosis of ASD, as genetic etiologies for autism continue to be discovered. Methods: Parent participants were reached through local and national autism support groups, in addition to support groups based in social media. The parental survey included an adaptation of the State Trait Anxiety Inventory, Likert scale questions regarding satisfaction, and demographic questions. Teacher participants were recruited from high schools in South Carolina by receiving the invitation letter via email from their respective school principals and also through an educational conference in Columbia, SC. Questions on the teacher survey focused on past experiences teaching students with AS, desired parental involvement, and desired knowledge regarding the student. **Results:** Of the total respondents (N = 172), 101 parent participants met the inclusion criteria. Their baseline anxiety was significantly lower than their anxiety regarding their child's school experiences. Overall, parents tended to be satisfied with teacher qualities, but less satisfied with the education experience as a whole. 10 teacher participants were interviewed and had a good overall understanding of the well-known characteristics of AS, and they desired knowing strategies for handling different situations that may occur in the classroom, as well as certain "triggers" that may upset the student. **Conclusions:** Teachers expressed interest in parent contact, yet a noticeable subset of parent respondents (37%) found it difficult to communicate with their child's teachers. Based on the findings of this study, the educational tool incorporates information teachers desired to know, and can assist initiating communication between parents of a child with AS or HFA and their child's teachers.

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## **List of Abbreviations**

Asperger syndrome
1 2 3
Autism spectrum disorder
High-functioning autism

#### Chapter 1. Background

The number of students with autism spectrum disorder (ASD) in schools, and in turn in regular education classrooms, is on the rise, but the quality of their school experience has been questioned (Kasari, Freeman, Bauminger, & Alkin, 1999; Humphrey, 2008). Children with ASD are over 20 times more likely to be excluded and/or bullied by their peers, and teachers have reported having more difficulty including these students effectively compared to students with other special educational needs (Humphrey, 2008). However, it has been found that parents of children with ASD believe that inclusive education improves the chances of the child to lead a normal life. In addition, individuals who work with these children were found to believe that inclusive education benefitted the student's social skills and taught diversity to the other students (Waddington & Reed, 2006). One previous study that focused on teacher perspectives of inclusive education of students with HFA in high school showed there was no significant difference between regular education teachers' and special education teachers' feelings regarding inclusive education, though special education teachers were slightly more likely to be in favor (Kieran, 2012). Our literature review reveals significantly more investigation directed toward students with autism in primary schools. Since primary schools are vastly different settings than high schools, more research needs to be completed that can be of use to both parents of high school students with ASD, and in particular AS, and high school teachers.

Asperger syndrome is a diagnosis on the autism spectrum and is, at the forefront, a social disorder. The syndrome received its name from an Austrian pediatrician named Hans Asperger, who described children from his practice in 1944 appearing to have normal intelligence, but lacking communication skills, failing to portray empathy, appearing physically awkward, and having extreme interest in one single topic. The diagnosis did not come to the forefront until Dr. Lorna Wing published case studies about children with similar symptoms in the 1980's. She coined the name "Asperger's syndrome" and the diagnosis became distinct in 1992, and then was added to the *DSM-IV* in 1994 (Myles & Simpson, 2002; National Institutes of Health, 2013).

According to the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text rev.; *DSM-IV-TR*; American Psychiatric Association, 2000), the diagnostic criteria for AS includes "qualitative impairment in social interaction; restricted repetitive and stereotyped patterns of behavior, interests, and activities; clinically significant impairment in social, occupational, or other important areas of functioning; no clinically significant general delay in language; no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than social interaction), and curiosity about the environment in childhood" (p.84). Although the newest edition of the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM-V*; American Psychiatric Association, 2013) has bundled separate diagnoses considered to be on the spectrum, including AS, into an all encompassing diagnosis of autism spectrum disorder, some individuals on the spectrum are still going to show the distinct characteristics associated with AS. The term HFA will still apply to those with autism who have a higher IQ.

Additionally, individuals with a well-established diagnosis of AS previous to the release of this new manual will retain their diagnosis. Therefore, the findings of this research study will still be of use to this population in the future.

Globally, individuals with this diagnosis tend to be socially awkward, deficient at understanding nonverbal clues, unaware of social standards, inappropriate in their social behaviors and unable to understand and appreciate thoughts and feelings of others (Myles & Simpson, 2002). However, compared to other disorders on the autism spectrum, individuals with AS classically desire having social interactions with others and can sense the differences between themselves and their peers (Myles & Simpson, 2002; Koning & Magill-Evans, 2001).

Intellectually, individuals with AS typically have average or above average measured intelligence (Gallagher & Gallagher, 2002), generally meaning an IQ of 86 or above. This renders it common for these students to be included in regular education classrooms. Indeed, many of these students are considered to be intellectually gifted (Gallagher & Gallagher, 2002). More students diagnosed with AS are pursuing postsecondary education (Smith, 2007; Graetz & Spampinota, 2008), and there are websites such as www.thinkcollege.net that promote students with all kinds of learning and social disabilities, including AS, pursuing college. These factors make it all the more important for these students to have a better opportunity to succeed in high school.

It is common for individuals with AS to go without a diagnosis until later compared to other diagnoses on the autism spectrum (Robertson, Chamberlain & Kasari, 2003). The Centers for Disease Control and Prevention study estimates the median age of diagnosis for AS to be over 6 years (CDC, 2012), while a previous study estimated up

to 11 years of age (Howlin & Asgharian, 1999). This is compared to a diagnosis at 3-4 years of age for autistic disorder (CDC, 2012) and this difference is likely because children with AS generally do not have delays in language development (NIH, 2013). Parents of a child with AS are more likely to experience more frustration and greater delays before a diagnosis is reached, as compared to more severe autism spectrum disorders. It is not uncommon for a child with AS to not receive a diagnosis nor receive any resources until they have completed primary school (Howlin & Asgharian, 1999), making it essential for secondary school teachers and parents both to have information available that is applicable to this age range.

As students transition from primary to secondary school, there is an increase in the number of interactions with both faculty members and classmates. As they enter this larger environment, it is a challenge posed to students to establish relationships and gain a sense of belonging. (Dijkstra, Cillessenn, & Borch, 2012). Dijkstra et al. (2012) showed that adolescents tend to base their peer relationships on choosing an individual that is similarly popular or more popular than they are themselves. Many adolescents with AS are eager to form friendships, but their "social naivety" can lead to being an outcast in the classroom (Humphrey & Lewis, 2008a).

One study conducted by Locke, Ishijima, Kasari & London (2010) demonstrated that adolescents with high-functioning autism experience significantly more loneliness and poorer friendship quality compared to their peers in a regular education classroom setting. In addition, 71.4% of adolescents with autism in this study felt isolated, in contrast to 92.4% of their unaffected peers feeling connected and recognized in their classroom (Locke et al., 2010). Considering the characteristic social challenges an

individual with AS faces, it is more challenging for these students to engage with their peers and reach a status of popularity. In turn, it is more challenging for these students to attain friendships with their peers, which leads to an increase in feelings of loneliness and a decreased quality of friendships.

In addition to these findings of increased loneliness and poorer friendship qualities, Humphrey (2008) has shown students with ASD are over 20 times more likely to be bullied and/or excluded in the school setting compared to students without ASD. The students' difficulties understanding and appropriately participating in social interactions make them easy targets for ridicule (Humphrey & Lewis, 2008a). Humphrey and Lewis (2008a) found that bullying and teasing happened to students on the autism spectrum in school at strikingly high rates. Incidents noted in the study included both name calling and physical violence. It has been concluded that adolescents with AS have a greater sense of threat, feel under appreciated by their classmates, and feel that they are treated indifferently (Pisula & Lukowska, 2011). Adolescents with AS also perceive less global support, appraisal, and emotional support compared to their unaffected peers (Pisula & Lukowska, 2011). It is apparent through these various findings that there is still progress to be made regarding improving the educational setting for students diagnosed with AS.

While the difficulties with social interaction often lead to a student with AS being ostracized from their peer group, this is not the only challenge noted in the inclusive education setting. Often, students diagnosed with AS are considered more arduous to include in the classroom compared to students with other special educational needs (House of Commons Education and Skills Committee, 2006). In study conducted by

Ashburner, Ziviani & Roger (2009), teachers reported students with ASD as exhibiting more anxiety, depression, shyness, withdrawal, oppositional behaviors, aggressive behaviors and attention deficits compared to their typically developing peers. This same study found the students with ASD were not performing to their intellectual capabilities as their other classmates were, presumably because of their emotional and behavioral difficulties (Ashburner et al., 2009).

Often, schools will provide students with AS some type of support staff to help them in regular education classrooms. Although this is an extra source of support for the student and can ease any academic difficulties, it can also hinder any attempt of the student to blend in or appear "normal." It may also interfere with how the teachers are able to include these students in the classroom (Humphrey & Lewis, 2008b). However, research has also shown many teachers believe inclusion has ample benefits for the student, including a greater sense of normalcy, social skill development, and the opportunity for other students to become diversified (Waddington & Reed, 2006). Kasari et al. (1999) reported that the majority of parents in their study also preferred mainstreaming of their child with autism at least part time, either for academic reasons or in order for their child to receive non-academic interactions with other students. Since inclusive education has been shown to be a desirable option for students with higher functioning autism and especially AS, we believe further research into how to improve this process will be of value.

The transition from primary school to secondary school encompasses switching from having one to two teachers for the majority of the day to having multiple teachers, each focusing on their own area of expertise. Therefore, this transition leads to students

having more teachers, and likewise teachers having more students for less periods of time. As can be assumed, this increased number of relationships overall may lead to weakened individual student-teacher relationships, as well as parent-teacher relationships. It has been shown that parental satisfaction of communication with their child's school is significantly decreased if the student is on the autism spectrum or has other special education needs (Zablotsky, Boswell & Smith, 2012). If a teacher is not in tune with a student who has AS or HFA and their characteristics, the student could be viewed as inattentive and uninterested in making positive relationships (Robertson et al., 2003).

Robertson et al. (2003) found that the relationships children form with their teachers in a primary school general education class including students with HFA are associated with subsequent peer relationships and the child's level of social inclusion. As discussed previously, students with AS are deficient in social interaction and more likely to be excluded by their peers. It is likely for these negative, misinterpreted associations to strengthen as a student with AS moves through the school system, and it is important for high school educators to be aware of this pattern if it is occurring, so they have an opportunity to reevaluate and improve the situation.

Lee, Harrington, Louie & Newschaffer (2008) revealed that, generally, parents of children on the autism spectrum perceive a lower quality of life for their children. Parents have also noted feeling that their child has an "invisible wheelchair" (Brewin, Renwick, & Schormans, 2008). As described earlier, AS is not an easily distinguishable diagnosis and, many times, these children can have a diagnostic odyssey that takes several years. It has been described in the literature and reaffirmed that when children have an apparently normal appearance, it may be harder to others to pick up on and

believe that the child has a disability, lowering the support that child may receive (Brewin et al., 2008). These parents also have higher concern for their child's well being compared to parents of children with attention deficit disorder/attention deficit hyperactivity disorder or unaffected children, measured by the National Survey of Children's Health. Specific concerns included their child having learning difficulties, as well as their child being bullied (Lee et al., 2008).

Zablotsky et al. (2012) showed that parents of students with ASD and without ASD overall display a positive correlation between parental satisfaction and parental involvement in the school setting. Parents of a student with ASD were more likely than parents of a student without ASD to attend parent-teacher conferences and meet with the school guidance counselor. However, parents of children with special educational needs commonly addressed unsatisfactory levels of communication with teachers (Zablotsky et al., 2012). Parents have also expressed an interest in teachers receiving more training on educating students with ASD and AS (Jindal-Snape, Douglas, Topping, Kerr, & Smith, 2005).

There are resources available for teachers that cater to educating a student diagnosed with AS (Williams, 1995; Myles & Simpson, 2003; Barnhill, 2004). Williams (1995) published guidelines focusing on seven characteristic features of students with AS and correlating suggestions for the classroom. The features included in these guidelines are insistence on sameness, impairment in social interaction, restricted range of interests, poor concentration, poor motor coordination, academic difficulties and emotional vulnerability (Williams, 1995). Barnhill (2004) provided a resource for families and educators highlighting the AS characteristics of theory of mind deficits, social skill

challenges, verbal and nonverbal communication challenges, behavioral and mental health challenges, and academic challenges. She also supplies strategies that encourage skill development in these areas. Suggestions based on known characteristics of students with AS are practical and need consideration in a classroom setting. However, there has been little, if any, research focusing on what information teachers would want about the diagnosis of AS itself based on their experiences or lack thereof, or what specific information they would want about the student in their classroom.

Although the prevalence of AS has not been well established, it was estimated in 2012 that 1 in 88 children were on the autism spectrum (CDC, 2012). Recently, the CDC (2014) published a new study that estimated an increase to 1 in 68 children on the spectrum. As has been evident in the last few decades, the incidence of autism continues to rise. The etiology of autism has been at the forefront of much research, as the majority of cases of ASD have no known cause (Huguet, Ey, & Bourgeron, 2013).

However, a review of several studies focused on the genetics of autism published by Huguet et al. (2013) estimated that a genetic cause could be identified up to 25% of individuals with ASD. The most common genetic differences being identified in individuals with ASD were chromosomal rearrangements, *de novo* copy number variants, missense mutations, and possibly small effects from single nucleotide polymorphisms (Huguet et al., 2013). Identifying additional genetic causes of autism will likely continue to be the focus of much research, as it is helping to define what was once such an enigma.

Students with a former diagnosis of AS or a diagnosis of HFA with characteristics similar to AS will likely continue to have communication and socialization deficits through adolescence and into adulthood, though early intervention has been shown to be

beneficial (NIH, 2013). Research based interventions focused on improving communication and socialization for students diagnosed with ASD are becoming increasingly popular, and it is essential for schools to consider these interventions as they have been shown to have a positive effect in the student (Koegel et al., 2012). Encouragingly, more students with AS are now viewing college as a postsecondary option than have been noted in the past decades (Graetz & Spaminato, 2008). There has been limited research conducted regarding students with AS in public high schools, and it is vital for these students to be successful in secondary school so they have an opportunity to move forward and succeed academically.

## **Chapter 2**

Parental Satisfaction and Teacher Perspectives on Inclusive Education of Students with Asperger Syndrome: An Educational Tool<sup>1</sup>

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<sup>&</sup>lt;sup>1</sup> Warren, H.E., Ferrante, R.R., Zvejnieks, D. & Hock, R. To be submitted to *Research in Autism Spectrum Disorders*.

#### 2.1 Abstract

**Purpose:** This study aimed to evaluate parental satisfaction and anxiety regarding the high school educational experiences of their child with a previous diagnosis of Asperger syndrome (AS), as well as educators' understanding of the diagnosis and what information they deemed important to know about the student. The goal of this study was to develop an educational tool that would aid in initiating communication between parents of a student with AS, or with a new diagnosis of high-functioning autism (HFA), and their teachers. This would be an additional resource of use to pediatric genetic counselors that frequently see families regarding a diagnosis of ASD, as genetic etiologies for autism continue to be discovered. Methods: Parent participants were reached through local and national autism support groups, in addition to support groups based in social media. The parental survey included an adaptation of the State Trait Anxiety Inventory, Likert scale questions regarding satisfaction, and demographic questions. Teacher respondents were recruited from high schools in South Carolina by receiving the invitation letter via email from their respective school principals and also through an educational conference in Columbia, SC. Questions on the teacher survey focused on past experiences teaching students with AS, desired parental involvement, and desired knowledge regarding the student. **Results:** Of the total respondents (N = 172), 101 parent participants met the inclusion criteria. Their baseline anxiety was significantly lower than their anxiety regarding their child's school experiences. Overall parents tended to be satisfied with teacher qualities, but less satisfied with the education experience as a whole. Ten teacher participants were interviewed and had a good overall understanding of the well-known characteristics of AS, and they desired knowing strategies for handling different situations that may occur in the classroom, as well as certain "triggers" that may upset the student. **Conclusions:** Teachers expressed interest in parent contact, yet a noticeable subset of parent respondents (37%) found it difficult to communicate with their child's teachers. Based on the findings of this study, the educational tool incorporates information teachers desired to know, and can assist in initiating communication between parents of a child with AS and their child's teachers.

#### 2.2 Introduction

As more children are being identified as being on the autism spectrum, it is becoming a more significant need for educators to be aware of what the diagnosis encompasses and have resources on how to successfully educate these students. Asperger syndrome (AS) was formally a distinct diagnosis on the autism spectrum, and it is characteristic for individuals with this diagnosis to have difficulties understanding social cues and acting appropriately in social situations (Myles & Simpson, 2002). However, these individuals typically have average to above-average intelligence (Gallagher & Gallagher, 2002), so students with AS often are in an inclusive classroom setting, meaning they are enrolled in regular education classes.

The difficulties with social interaction that these students experience have been associated with having challenges in school. It has been shown that students with AS are more likely to be bullied or excluded by their peers, have more feelings of loneliness, and experience poorer friendship qualities (Humphrey, 2008; Locke et al., 2010). In addition, students diagnosed with AS have been considered harder to include in the classroom setting compared to students with other special educational needs (House of Commons Education and Skills Committee, 2006). However, many educators believe there are

numerous benefits for including these students in the classroom (Waddington & Reed, 2006).

While Asperger syndrome (AS) has been bundled into an all-encompassing autism spectrum disorder diagnosis in the current version of the *Diagnostic and Statistical Manual of Mental Disorders*, (5th ed.; *DSM-V*; American Psychiatric Association, 2013) individuals with a prior diagnosis of AS still have a particular set of characteristics that are distinct from other diagnoses on the spectrum. The population of students that are of interest in this research study had a prior diagnosis of AS. However, the results of this study will be applicable to those individuals with a diagnosis of AS who have not yet reached high school, as well as individuals who receive a *DSM-5* diagnosis of autism spectrum disorder and show characteristics of the former AS. The *DSM-5* specifies severity levels within the autism spectrum disorder, with Level 1 diagnoses requiring the least assistance and Level 3 diagnoses requiring the most assistance. Since individuals with a previous diagnosis of AS do not require much assistance and are commonly being included into regular education classrooms, the new diagnoses will be considered Level 1, which may also be known as HFA.

This study aimed to assess parental satisfaction and anxiety regarding the inclusive education of their high school aged child with AS, as well as assessed teacher perspectives regarding the possibility of, or experiences with, having a child with AS in their classroom. We hypothesized parents have low satisfaction regarding their child's school experiences, which in turn lead to higher anxiety levels when they considered these experiences. In addition, the teachers were asked to discuss what kinds of

information they deemed important for the parents to provide once it was known the student was going to be in their classroom.

The end goal of this study was to create a simple educational tool that can be individualized to students to distribute to both families and teachers, increasing awareness of the characteristics of AS, as well as providing a framework for discussion based upon the teachers' desired knowledge about the diagnosis. This tool will ideally initiate interaction between parents of a child with AS or HFA and their child's teachers.

Though the purpose of this study was not based in genetic causes of autism, it has been estimated that up to 25% of individuals with ASD can be identified as having a genetic cause (Huguet, Ey, & Bourgeron, 2013). This statistic sheds light on how many individuals with ASD may be referred for genetics evaluations, at which there is an opportunity to provide these families with resources regarding their child's education, among many other things. This resource will be a useful asset to pediatric genetic counselors who routinely see children with ASD, a portion of which will have a prior diagnosis of AS or a new diagnosis of HFA.

#### 2.3 Materials and Methods

The survey participants for quantitative analysis were parents of a child previously diagnosed with AS who was between the ages of 14 and 18, was enrolled in public high school, and was enrolled in a regular education class for at least one core class per day.

The teacher participants were teachers from public high schools within the state of South Carolina. To acquire a diverse study population, teachers were selected from

schools within both rural and urban cities, with rural cities having <50,000 inhabitants, as defined by the U.S. Census Bureau.

## 2.3.1 Parent Survey Information

The quantitative survey for parents consisted of three sections. The first section was a 10-question Likert scale section for parents to agree or disagree with statements about their satisfaction with the school experiences of their child with AS. The second section was based on the State Trait Anxiety Index (STAI) as adapted from the State-Trait Anxiety form Y published by Speilberger, Gorsuch, Lushene, Vagg, & Jacobs (1983). It consisted of 20 items that measured general levels of anxiety, followed by a second scenario measuring levels of parental anxiety specifically related to their child's school experiences, using the same 20 items after being directed to think about their child's experiences. A Cronbach's alpha was conducted on this adapted form of the STAI to test its reliability, and it was shown to be reliable (10 items;  $\alpha = .76$ ). The final section collected limited demographic information. No identifying information was collected on the survey itself. All responses were anonymous. If a participant wished to participate in a drawing for an incentive gift card, she or he voluntarily left their contact information in a separate section of the survey.

The parent survey was posted on www.SurveyMonkey.com. The hyperlink for the parent survey was posted via autism support websites and/or their social media sites in the event that they were willing to host the survey, and also was forwarded to members of the Family Connection of South Carolina AS support group through email. The invitation to participate was posted with the survey such that the participants viewed the

letter prior to entering the survey site. The invitation letter and parent survey can be viewed in Appendix A and Appendix B, respectively.

## 2.3.2 Teacher Survey Information

An invitation to participate in a 10-15 minute telephone interview was distributed to teachers in the selected districts via their school email addresses with permission from the school principal. Teachers were also invited to participate at the Fall DCDT State Transition Conference in Columbia, SC on October 24-25, 2013. A semi-structured interview outline was followed and administered by the principal investigator on the phone using the recording program Audacity. The interviews were recorded for later transcription by the principal investigator, with any identifying information deleted from the transcription to ensure anonymity was protected. Teachers who participated had the choice to share their contact information for an incentive gift card. The contact information was shredded and discarded after the drawing was completed. The teacher invitation letter and survey question can be located in Appendix C and Appendix D.

## 2.3.3 Statistical Analysis

Data from SurveyMonkey.com was transferred to Excel spreadsheets and organized for analysis. Frequency, counts, and percentages were used to review ordinal categorical data related to the parental satisfaction portion of the survey, using Microsoft Excel software. Statistical Package for the Social Sciences (SPSS), version 22.0 was used for quantitative data analysis. T-test analysis was used to compare parental anxiety in everyday life and parental anxiety when considering their child's school experiences. As the majority of the questions on our survey follow the Likert scale, we reviewed these item by item and reviewed as categorical groups, as necessary. We used bar graphs to

display this data visually. Pearson's correlation analysis compared ordinal variables within the demographic information, such as the grade level of the student. ANOVA analysis was used to compare nominal variables within the demographic information, such as gender and marital status for possible statistically significant associations.

### 2.3.4 Qualitative Analysis

Transcriptions of the teacher surveys were analyzed using the grounded theory method for social sciences. Themes were identified and categorized from phrases and words that are common to multiple participants. If direct quotes were used from the transcriptions, no identifying information of any participant was associated with the quotations. Full transcripts of the interviews can be located in Appendix E.

#### 2.4 Results

#### 2.4.1 Parental Survey Results

Responses to the parent survey were collected from September, 2013, through December, 2013. 172 parents completed the survey. According to the inclusion criteria, only respondents who had a child with an official diagnosis of AS who currently attended public high school and was enrolled in at least one regular education classroom could complete the survey. Based on these criteria, 71 surveys were excluded and 101 of the total 172 respondents' responses were analyzed.

2.4.1.1 Parental demographic information. For these 101 respondents, Table 2.1 shows the demographic information provided in the surveys. Some respondents chose to not answer certain questions, which explains the discrepancy of n between these categories.

Table 2.1:

Demographics of Parent Respondents

Respondent Gender	Gender of Respondent's Child with AS	Child's Class Standing		
Male Female 82	Male Female 65 22	<u>Fr</u> <u>So</u> <u>Ju</u> <u>Se</u> 21 11 13 34		
No. of Meetings with Teacher in Past Year				
$\frac{0}{1}$ $\frac{1-3}{21}$ $\frac{4-7}{35}$ $\frac{8+}{30}$	\[     \frac{\left\{12k}}{4}  \frac{\left\{12,001-30k}}{12}  \frac{\left\{30,00}}{12}   \]	$\frac{01-50k}{11}$ $\frac{$50,001-100k}{22}$ $\frac{>100k}{11}$		
1 21 35 30	4 12 1	11 32 11		
Parental Level of Educat	ion			
Did not finish HS HS dip	loma/GED Some college A			
1	10 27	19 13 12		

## **Marital Status**

Single, never married	Married	Separated	Divorced	Widowed
6	62	5	10	1

2.4.1.2 Parental anxiety. Results showed a statistically significant increase in anxiety score when parents considered their child's education experiences compared to their baseline anxiety, (t(76) = 4.14, p < .001), using a t-test analysis. The baseline anxiety scores of the parents were not significantly affected by whether the respondents themselves were male or female, or whether their child was male or female. The baseline anxiety score was also not significantly affected by their child's class standing, the number of times they met with their child's teachers, their personal level of education, or their marital status. It was significant, however, that the respondent's household income was negatively correlated with their baseline anxiety score. See Table 2.2 for complete statistical information.

Table 2.2: Demographic effects on baseline parental anxiety

ANOVA	df	F	p
Respondent male or female	(1, 80)	.22	.64
Child male or female	(1, 82)	.063	.80
Respondent marital status	(4,77)	1.40	.24
Pearson's Correlation	n	r	p
Child's class standing	76	06	.31
Number of meetings with			
teachers in the past year	82	.16	.08
Respondent level of			
education	79	.03	.40
Respondent's family income	75	29	.006*

Note: F values represent analysis performed by ANOVA; r values represent analysis performed by Pearson's correlation

Parental anxieties when they considered their child's school experiences only showed a significant positive correlation with how many times the parents had met with the teachers in the past year. Their gender, their child's gender, their child's class standing, their family income, their educational level, and their marital status were not significant factors in their anxiety when considering their child's education. See Table 2.3 for complete statistical information.

<sup>\*</sup>Statistically significant (p < .05)

Table 2.3:

Demographic effects on parental anxiety when considering their child's education

ANOVA	df	F	p
Respondent male or female	(1, 78)	.34	.56
Child male or female	(1, 80)	.73	.39
Respondent marital status	(4, 75)	1.40	.68
Pearson's Correlation	n	r	p
Child's class standing	74	.002	.49
Number of meetings with			
teachers in the past year	80	.33	.001*
Respondent level of			
education	77	.11	.16
Respondent's family income	73	14	.11

*Note:* F values represent analysis performed by ANOVA; r values represent analysis performed by Pearson's correlation \*Statistically significant (p < .05)

2.4.1.3 Parental satisfaction. The respondents were asked 10 Likert scale questions regarding their child's education, one of which asked specifically about their current level of satisfaction. Using the parental responses to this question, significant negative correlations were found between both their level of satisfaction and their child's class standing, and also their level of satisfaction and the number of times they had met with the teacher in the past year. There was a significant difference in the satisfaction levels between respondents who had differing marital statuses, and there was also a difference in satisfaction levels based on whether the respondent had a male or female child. Respondents who were married had the highest level of satisfaction, and respondents who had male children had higher satisfaction compared to respondents with female children.

Factors that were not significantly correlated with parental level of satisfaction were their own education level, their family income, or whether they were male or female. See Table 2.4 for complete statistical information.

Table 2.4:

Demographic effects on parental satisfaction regarding their child's education

ANOVA	df	F	p
Respondent male or female	(1, 83)	.03	.87
Child male or female	(1, 84)	5.81	.02*
Respondent marital status	(4, 79)	3.38	.01*
Pearson's Correlation	n	r	p
Child's class standing	79	210	.03*
Number of meetings with			
teachers in the past year	85	43	.001*
Respondent level of			
education	82	04	.35
Respondent's family income	79	003	.49

Note: F values represent analysis performed by ANOVA; r values represent analysis performed by Pearson's correlation

2.4.1.4 Parental opinions on school experiences. The 10 Likert scale questions included in the parent survey regarding their child's school experiences were analyzed for frequency. Overall, exactly half of parent respondents (50%) agreed or strongly agreed that their child's teachers are meeting educational needs, while 37% disagreed or strongly disagreed with that statement. There was a slightly higher percentage (45%) of parents who were not satisfied with their child's school experience than those who were satisfied (43%). Approximately 41% of parent respondents agreed or strongly agreed that their child's teachers encourage their students to learn, while 37% disagreed or strongly disagreed with that statement. See Figure 2.1 for complete information.

<sup>\*</sup>Statistically significant (p < .05)

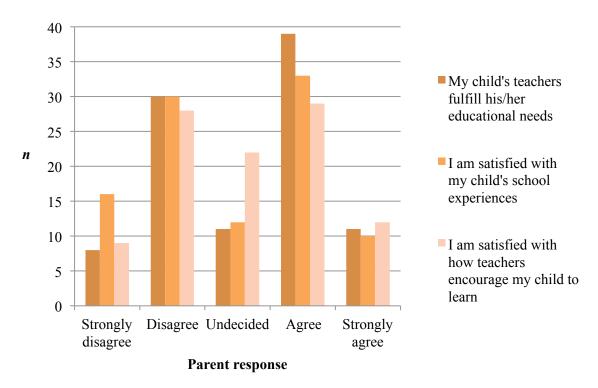


Figure 2.1: Parental responses on their satisfaction with teachers

The largest percentage of parents (39%) disagreed or strongly disagreed with the statement, "The teachers at school do not support my child's emotional needs." 38% of parents agreed or strongly agreed, while a noticeable approximately 25% of parents were undecided. 47% of parent respondents disagreed or strongly disagreed that their child's teachers were difficult to clearly communicate with, compared to 37% of parents who did find it difficult to communicate with their child's teachers. 55% of parents agreed or strongly agreed with the statement, "Teachers do not understand my child's personality," while only 31% disagreed or strongly disagreed with that statement. See Figure 2.2 for complete information

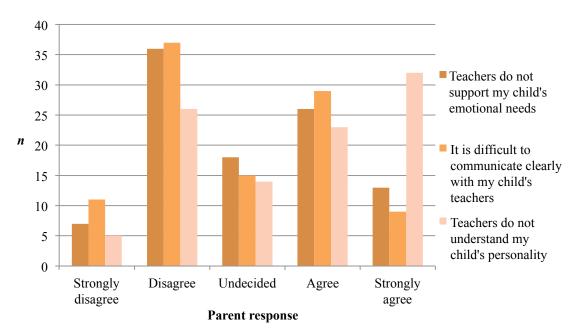


Figure 2.2: Parental responses on teacher support, communication, and understanding

Regarding how their child is treated at school, over half of parent respondents (53%) agreed or strongly agreed that their child does complain about how he/she is treated by other students, while 38% agreed or strongly agreed that their child complains about how he/she is treated by teachers. See Figure 2.3 for complete information.

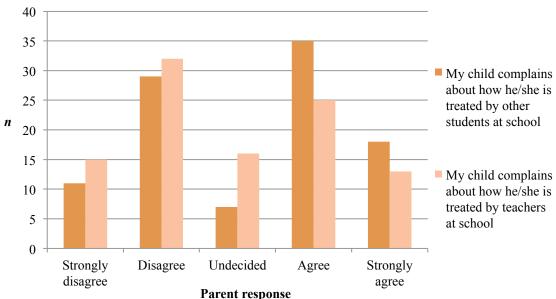


Figure 2.3:

Parent responses on how child is treated by peers/teachers

Over half of the parent respondents (51%) agreed or strongly agreed that their child does tell them of things they are doing with friends at school. 45% of parent respondents believe that their child's teacher is able to manage the students in their classroom, while a noticeable percentage (25%) were undecided about this topic. See Figure 2.4 for complete information of the responses.

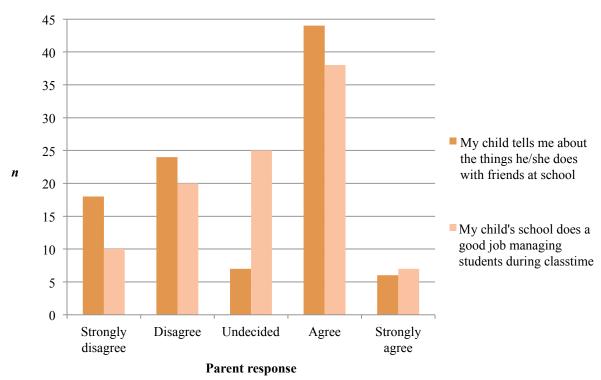


Figure 2.4: Parental responses on child's friendships with peers and teacher management

### 2.4.2 Teacher Results

Ten high school teachers from the state of South Carolina were interviewed from September, 2013 to February, 2014. All teacher respondents completed the survey in its entirety and none of the results from the interviews required exclusion.

2.4.2.1 Teacher Demographic Information. The teachers who participated in this study taught a range of subjects (see Table 2.5). The highest percentage taught science, while the next highest percentage taught a form of special education or occupational support. Seven of the ten teachers taught in regular education classrooms, while the remaining three were teachers of some form of special education or extra support.

Table 2.5: Subjects Taught by Teacher Respondents

Subject	n
Science*	4
Special Ed/Occupational support	3
Sports Medicine	1
Drama/Theater	1
English	1

<sup>\*</sup>Science includes teachers of Honors Biology, AP Biology, Chemistry, and AP Environmental Science

There were eight female respondents and two male respondents. All but two had previous experience teaching a student with known diagnosis of AS, but two teachers noted that they had previous students who they think should have had the diagnosis (see Table 2.6). There were four respondents from schools in an urban city of South Carolina, as defined by the U.S. Census Bureau as having >50,000 inhabitants; the remaining six respondents taught at schools in rural cities.

Table 2.6:
Previous Respondent
Experience Teaching
Students with AS

# of Students with Known Diagnosis	n
0	2
1-2	3
3-5	5

2.4.2.2 Thematic Analysis. In addition to demographic questions, respondents were asked open-ended questions regarding educating students with AS and their thoughts, experiences, challenges they have had or believe they would have, support systems, and desired interaction with parents. Themes were derived from the 10 responses and analyzed for frequency of response. Full interview transcriptions can be located in Appendix E.

The majority of teacher respondents noted both social difficulties (n = 8) and intelligence (n = 6) when asked what came to their mind when they thought about AS. See Figure 2.5 for the subthemes of social difficulties that were analyzed from the interviews. The following statements quoted directly from participants' responses illustrate these two themes:

- Generally, I guess children that experience... social issues. They don't know how to interact with their peers or they're kind of standoffish and they can be very bright. Maybe not in all their subjects, but they can be very bright and they don't know how to socially get along in the classroom.
- Students that mostly have difficulties in social situations. But, usually they're very intelligent.
- I just, I had one student who was in a broadcasting class who was very fixated on providing readings from the Bible on our broadcast and I had to... I explained to him that because we are a public school that we are not at liberty to do that. He... I thought he understood and then it showed up again on the announcements, I was like ahhh! He was very focused on that and that really wasn't like a bad, he was not being... he was not disobeying; he was just focused on that. He insisted that we do that.
- They're like little human encyclopedias and they see things in a really interesting way and there are a lot of good things that will come from these kids, too.

However, a few respondents had different thoughts when considering this question. The following quotes were taken directly from the interviews:

- Hmm, kind of like Down syndrome type of child, you know, kind of disease. It's kind of like that.
- Well, the Asperger's kid had a lot of problems, a whole lot of problems. The high functioning autistic I haven't had nearly the problems with but the Asperger's kid I have loads of problems with. Huge behavior problems, huge academic problems, emotional problems.

Several teachers also noted their concern for the students with AS being bullied or not being accepted by their peers.

I think mostly since the syndrome isn't, I mean, it's not like kids understand, other kids, understand the syndrome. And it's sometimes they're not readily accepting of students with it [sic], but had one student, I think it was 2 years ago, you know, that the other kids thought he was kind of weird and didn't quite understand, you know, what was the matter or how to deal with him.

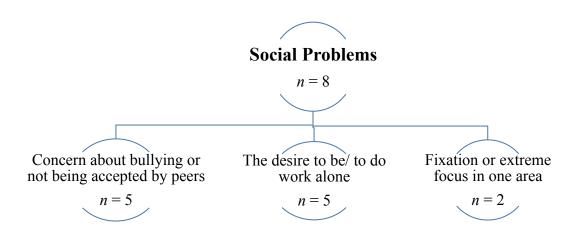


Figure 2.5: *Identification of Social Problems as a Major Feature of AS* 

Another theme that arose from the respondent interviews was the desire to have contact with parents of a student with AS (See Figure 2.6 for representation of this theme and subthemes). Teacher respondents were asked what kinds of contact they would prefer, as well as information they would like to know about the student beforehand in order to be able to better provide for the student. All but one respondent desired contact

with the parents of students with AS for a variety of reasons. Communication methods that were preferred differed between respondents, with emails, phone calls, and face-to-face meetings all being mentioned. Information regarding how different situations were dealt with at home and any triggers that the student may have were both desired knowledge mentioned by several teacher respondents. Long-term goals for the student were also an interest to two teacher respondents. Select quotes mentioned below were chosen to represent a few of the thoughts mentioned by teacher respondents when considering parental communication.

- Again, I always feel like establishing contact in the beginning is one of the most important things. Opening up that channel is good. Just a heads up, so and so is having a rough day today or we had something happen this weekend and I'm kind of concerned about it this week. Again, prevention I think. But then, also, just the ability to get ahold of them via email or via phone if I really feel like I need to. And if they're concerned, always letting them know that I welcome any kind of contact whatsoever. Most of the times, it's really just answering your case manager here at school. But if the parent wants to come to school, that's great too. Just knowing how to get ahold of the parents when I need to.
- Well, just like with every other kid, the more a parent is involved, I think the better. We would always want to have conversations and parent visits and stuff like that. The more they're involved; I feel like the more successful the child is going to be.

What kinds of information would you like to know from the parents before having student with AS in your classroom?

If there's a problem, how to calm a child down. Especially if they got something that's going to hold them back a little bit, or any triggers that they may have, ways that they learn best [sic]. That's not for Asperger's, that's for every kid you know. How are they going to learn best, how do you prevent them from having a break down or something like that.

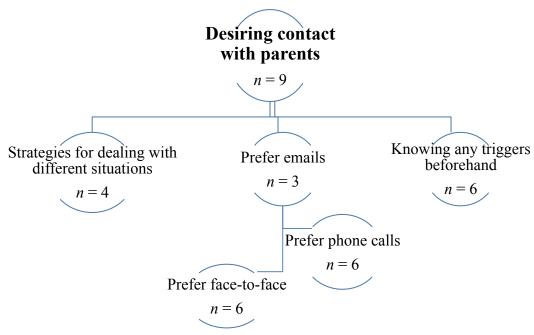


Figure 2.6: Teacher Desire to have Contact with Parents of Student with AS

Nine of ten teacher respondents interviewed felt that they had a support system at their school. Types of support mentioned included fellow teachers (including special education and exploratory teachers) (n = 4), a psychologist on staff or easily accessible (n = 3), administration resources (n = 3), and individualized education plan (IEP) related information (n = 2). The one teacher respondent who did not sense support at their school felt as if some information was privileged, but this was not felt by other teacher respondents. We included two quotes below to demonstrate different levels of support reported by our respondents, which likely represents a difference between their school environments.

Not a whole lot. We usually... we'll get IEP paperwork or something of what the kids may have. I hate to say but often times it's kind of like on a need-to-know basis and you don't need to know anymore. So, not a whole lot of support.

• Our teachers, like our special ed teachers, have... case loads. And then, we often had a speech therapist that worked with one of the kids with AS and they both were, you know, in very frequent communication and checking on the progress of the students. They were also a good resource for explaining things to these students that may be in a different way than how I had.

Of note, seven of the eight respondents that had previously taught a student diagnosed with AS reported that their experiences with the student in and out of the classroom were positive. As mentioned in earlier quotes, these students were overall perceived as intelligent and hardworking. We included a few quotes from the interviews that further justify this point.

- Really good (experiences). They have been eager to learn and, like I said, bright, able to catch onto concepts fairly quickly, but they often needed teaching methods that were different from the other students.
- Good (experiences), you know, never had any kind of issues with them. They were very focused on their education, very focused on being successful. But, I do remember kind of a dislike... they didn't like the bells, they didn't like assemblies, they didn't like really being out in the hallways much during class change.
- *They've (experiences) been really positive.*

One teacher respondent had additional thoughts during the interview that were not prompted by a question. This teacher addressed a perceived under-diagnosis of AS and embraced any additional knowledge they could be given about their student.

I think that students with Asperger's don't necessarily come with papers. We know that there are some out there with paperwork, but we also know that there are probably some students that we have that may have this issue but they just haven't been diagnosed for whatever reason. It (having a student with AS) gives you tools that you can use with all of your students and helps you with classroom management and helps you with students that may have some of these similar issues. So I think that's great; it's just knowledge. Just knowing that they're in there and knowing what you need to do to help. And experience having those students and treating them equal to everybody else,

and as a teacher your attitude towards them helps the students know how they need to respond as well.

#### 2.5 Discussion

The idea for this study originated from the authors' experiences interacting with parents of young adolescents diagnosed with AS, and seeing several families bring in a child with ASD to genetics clinics. School was always the center of a lot of focus, concerns, and questions, as it is for most parents. As discussed earlier, individuals with AS characteristically have some form of social hindrance, which may include social awkwardness, the inability to understand nonverbal clues, inappropriate social behaviors, and the inability to understand and show empathy for others (Myles & Simpson, 2002). However, many individuals with AS have an average to above average IQ score (Gallagher & Gallagher, 2002), which deems it appropriate for these students to be placed in a regular education classroom. As would be expected, this setting can pose difficulties for both the student and the teacher.

We wanted to both explore the current satisfaction and anxiety levels of parents who presently have a child in a public high-school setting, as well as hear from the side of the educators who have taught, or have the possibility of teaching, a student diagnosed with AS. We wanted to know what information was desired by teachers in public high schools about the diagnosis AS, but also what information could be provided about the student that would increase the teacher's comfort level with having that student in their classroom. Our end goal was to use this double-edged information to create an educational tool that incorporates what teachers deemed as helpful information to know, but also assists in initiating a relationship between the parents of a child with AS and their child's teachers. Genetics clinics frequently see individuals referred for a diagnosis

of autism, and this tool would add to the collection of resources on hand for these individuals.

The first anxiety score measured from parent respondents was their baseline, or general, anxiety, with higher scores being associated with higher anxiety. The only demographic that was included in this study that had a significant impact on parental baseline anxiety was household income. It has been seen previously that socioeconomic status in childhood and adulthood increases the risk of psychiatric disorders and, in addition, low social position in childhood is associated with depressive and anxiety disorders as an adult (Stansfeld, Clark, Rodgers, Caldwell, & Power, 2011). Our results showed a similar pattern; there was found to be a negative correlation between parent respondents' household income and baseline anxiety score, meaning that the more income there was in a family, the lower their anxiety score. There are numerous tolls that economic hardships have on individuals and their families, so our results showing that general anxiety is raised in these parents of lower income families was not unexpected.

As was expected, parental anxiety level regarding their child's school experiences was significantly higher than their baseline anxiety overall. This increase in anxiety could be due to a variety of factors, one of which may include concern over their child's teachers not understanding his/her personality. Indeed, it has been shown previously that teachers who are not fully aware of the characteristics of AS or ASD can view their students as inattentive and uninterested in making positive relationships (Robertson et al., 2003). In our study, over half of parents surveyed agreed that their child's teachers do not understand their child's personality, presumably adding to the parental stress felt when considering school experiences.

Other factors that may play a role in increasing parental anxiety include worry over their children not learning to the best of their ability, and also worry over their child being ostracized or bullied by their peers. The increased frequency of bullying observed against students with AS and ASD is well documented (Humphrey & Lewis, 2008a; Pisula & Lukowska, 2011), and we found that the highest percentage of parents we surveyed strongly agreed that their child does complain of how he/she is treated by their peers at school. Unfortunately, this was not unforeseen. There is much research in the area of improving communication and socialization for students with ASD (Koegel, Matos-Freden, Lang, & Koegel, 2012), so we can hope that in the future, more students will be receiving necessary therapy and will have a better chance to overcome their social obstacles.

Although there was an overall significant increase in anxiety when parents considered their child's school experiences, it is important to note that many parents were currently satisfied with their child's education. Most parents surveyed agreed that teachers were fulfilling their child's educational needs, were encouraging their children to learn, and were efficient at managing the students in their classroom. In addition, most parents surveyed disagreed that teachers were not supporting their emotional child's needs, that it was difficult to communicate with teachers, and that their child complained at how he/she was treated by teachers at school.

The communication levels between the parents and teachers of a student with AS was one of our main points of study. It has been seen previously that parental satisfaction regarding the communication level with their child's school is significantly decreased when the child has ASD or has other special education needs (Zablotsky et al., 2012).

The same study showed that both parents of children with ASD and children without ASD showed a positive correlation between satisfaction level and how involved they were in the school setting (Zablotsky et al., 2012).

In our study, most parents reported meeting with their child's teachers four to seven times in the past school year, which is a notable amount of meetings in a high school setting. However, the parental data that was analyzed for our study showed a significant positive correlation between how many times parents met with their child's teachers and the parent's anxiety level regarding their child's school experiences. In addition, there was a significant negative correlation between how often parents met with their child's teachers and their satisfaction level. These two findings are reasonable for our study population if considered in a different light, although the satisfaction finding is in opposition to the positive correlation between parental satisfaction and level of school involvement found by Zablotsky et al. (2012). We deduce that if a parent is more anxious and less satisfied, they are going to meet with their child's teachers more often. On the other hand, parents who are less anxious and more satisfied with their child's school experiences may not feel that meeting with teachers multiple times is necessary.

There were more significant factors associated with parental satisfaction regarding their child's education than parental anxiety. The most significant finding from our study regarding parental satisfaction was a significant negative correlation between the number of times parents met with their child's teachers and their level of satisfaction. Again, this can be explained by our previous point of view; if a parent is not anxious and is satisfied, they are not going to have a reason to set up several meetings with the teachers.

Other significant factors affecting parental satisfaction were their child's class standing, their child's gender, and the respondents' marital status. Our results showed that as students reached higher grade levels, the parents became less satisfied. One possible explanation of this is parent dissatisfaction of how their child's high school is preparing them for college. As mentioned earlier, more students with AS are enrolling in college than there have been in the past (Smith, 2007; Graetz & Spampinota, 2008), so their preparation may be getting more attention from parents than before. Our results also showed that parents of female students with AS were less satisfied when compared to parents of male students. All forms of ASD are known to be more common in males, and this may play a role in our finding. If teachers are not as keen on picking up characteristics of AS in females, it may hinder understanding the student herself and her needs. This is an area of the diagnosis of ASD that should be pursued further, as it was not the focus of this research.

The respondents' marital status was also shown to significantly impact their satisfaction with their child's education, with married respondents having the highest level of satisfaction overall. The other marital status options that were provided in the survey were single, divorced, separated, and widowed. Previous research has shown that there is a higher incidence of mental health concerns in individuals who are unmarried, divorced, and widowers (Lindstrom & Rosvall, 2012). While school satisfaction and mental health concerns are different entities, we believe that there may be an association between individuals who are not married and satisfaction levels overall, which could play a role in the higher incidence of mental health concerns previously discovered in this population.

Though our results showed that the respondents' reported gender was not significantly associated with their baseline anxiety, anxiety regarding their child's education, and their satisfaction with their child's education, this may need further investigation. Only three (3%) of our parent surveys that could be analyzed were completed by males. Therefore, we did not capture a large percentage of fathers' anxiety levels, satisfaction, or answers for the remaining Likert scale questions included on our survey.

In general, it is well known that women tend to be more open about personal issues and tend to seek out more social support than men. Recent studies expanding on this in the Internet setting showed that men were more likely to use the internet to perform tasks, including reading the news, and were more likely to use social media to find a date or to network for a job. Women were more likely to use the Internet to maintain relationships and specifically use social media to post public messages, post photographs, or send friend requests (Muscanell & Guadagno, 2011). Since the majority of the parent participants from our study were reached through social media outlets, it is not surprising that most respondents were women. In the future, other outlets could be considered to create a larger male response.

Overall, the parent respondents in our study were more likely to agree that their child's teacher was both meeting educational needs and encouraging students to learn. In addition, although 45% of parents were dissatisfied with their child's educational experiences, 43% of parents were satisfied. The largest percentage (45%) of parent respondents also believed that their child's teachers could manage their classroom. Although there is no previous study that is similar enough for comparison of these

numbers to see how they have evolved or how they compare to children without a diagnosis of AS, we are encouraged to see the percentage of parents who think that their child with AS is having a good educational experience.

Three questions with a negative inflection were included in the survey, and similarities in patterns of answers can be seen when compared to the other Likert scale questions. There was less than a 1% difference between parents who disagreed and agreed with the statement regarding teachers not supporting their child's needs, with the slightly higher percentage belong to parents who disagreed. Notably, almost 25% of parents answering this question were undecided on this statement. Noticeably more parents disagreed with the statement regarding their child's teacher being difficult to communicate with, meaning that parents are finding it feasible to contact teachers. However, over 37% of parent respondents did find their child's teachers difficult to communicate with, which is a significant group of parents who could benefit from assistance in this area. Our educational tool is intended to not only provide information about AS, but also to act as an aid to help parents and teachers communicate more effectively.

The statement, "Teachers do not understand my child's personality" was included in the survey because of previous research showing that teachers who are not in tune with a diagnosis of AS can view these students as inattentive or uninterested in making positive relationships (Robertson et al., 2003). Based on the well known characteristics of AS, it is plausible that students with AS who are showing extreme focus in the classroom and are not able to productively interact with fellow peers can be viewed in this more negative light.

In our study, only 31% of our parent respondents disagreed with this statement, meaning that they believe teachers do understand their child's personality. Over half of parent respondents agreed or strongly agreed that their child's personality was not understood by teachers, with this particular statement having the highest percentage of strongly agree responses of any survey question. Since this previous finding was confirmed in our study population, it is certainly an ongoing issue. One of our main goals with creating the educational tool is to address this topic in particular and to provide information to regular education teachers about the diagnosis of AS that they may not have had the opportunity to see before. In addition, the tool also provides more information on what to possibly expect having a student with AS in their classroom.

There were two survey questions regarding how parents felt their child was treated at school, both by peers and teachers. Teasing and bullying are two major concerns for students with AS, and the increased bullying frequency of students with AS and ASD has been brought up in the literature previously (Humphrey & Lewis, 2008a; Pisula & Lukowska, 2011). Over half of our parent respondents agreed or strongly agreed that their child does complain of how they are treated by peers at school. On the other hand, roughly half of parents also agreed or strongly agreed that their child told them of things they were doing with friends at school. These two items are not necessarily counterparts, as an individual can have friends, yet still be bullied by others. Previous research has shown that parents of a student with ASD may perceive a lower number of friends than the student reports him/herself, possibly because the student may classify peers who have similar interests as their friends, while parents consider friends as those with whom their child has mutual interactions and emotional interchanges (Kuo,

Orsmond, Cohn, & Coster, 2011). Of parent respondents, 37% agreed or strongly agreed that their child complains of how they are treated by teachers at school, which may not necessarily be bullying, but could in fact be repercussions of the misunderstanding of personality traits that has been brought up previously in other studies and in our study.

The teacher respondents in our study taught a variety of subjects. Three teachers were involved in teaching some type of special education, resource, or occupational support, and although the students we were focusing on in this study were in regular education classrooms, it was beneficial to hear these teachers' points of view. These teachers were likely more educated on ASD in their training as compared to strictly regular education teachers, although both sets of teachers were likely to have encountered a student with AS in their career. We attempted to recruit teacher participants from both rural and urban areas of South Carolina to control for the amount of resources the schools had; four of our teacher respondents were from schools in an urban city, while the remaining six taught at schools in rural areas.

Two teachers interviewed had no experience teaching a student with a known diagnosis of AS, so the majority of questions asked were hypothetical situations. The other eight teachers had a range of experience teaching students with a known diagnosis of AS, spanning from one student to five students in their career. The vast majority of teacher respondents mentioned social difficulties and intelligence when asked to put into words what came to their mind when considering AS. The one explanation of AS that compared the diagnosis to Down syndrome and had no overlap with any of the other teacher responses was from a teacher who had never had a student with AS in their classroom. Overall, it was encouraging to see how the majority of teacher respondents

had a good understanding of the general characteristics associated with the diagnosis of AS.

There were several different types of social problems that were mentioned by teacher respondents more than once. Half of the teachers interviewed had concern over students with AS being bullied or not being accepted by others in the classroom, as was also a concern seen from the results of the parent survey. Two teachers noted that previous students they had taught had extreme focus in one area and had difficulty concentrating on other things. Five teachers brought up how students they had previously taught were not proponents of working in groups or did not like speaking to others, and would rather work on tasks on their own. All of these findings neatly fit into the well-known characteristics of AS, meaning that overall these teachers had a good understanding of what all AS entailed because of their previous experiences.

As a group, the teachers interviewed overwhelmingly desired contact with the parents of their students with AS. The preferred mode of communication varied from teacher to teacher, but all but one respondent seemed to be open to receiving contact from the parents. In addition, most teachers felt that this communication was very important for the success of the student, and the more involvement from the parents, the better. A common piece of information that teachers wanted from the parents was strategies for dealing with different kinds of situations. For example, strategies that have worked at home for how to calm the child down if they become overwhelmed or anxious.

Another topic that teachers wanted information about was specific things that may make the student upset so they could avoid these things all together. Examples brought up by teacher respondents included wanting to know if the student was not okay with changing seats, could become overwhelmed easily if too many tasks were given, or was sensitive to certain topics. Teacher respondents also desired to know how sensitive the student was to what other students may say, so they could be sure to do the best they could to surround the student with AS with more accepting and understanding peers. In addition, two teachers were interested in knowing the student's long-term goals. Both of these teachers were special education teachers, so their experiences likely were with students who were not as highly functioning as is typically thought of with students with AS.

Limitations of our study include several factors that could have impacted our results. Most parent respondents were reached via social media advertisement and our parent survey was strictly offered online, which biases our study population to those who have access to a computer and the Internet. In addition, as discussed earlier, the vast majority of our parent respondents were mothers, likely because of social media was our main tool for contacting parents. Females have been shown to use social media for building relationships and posting public links, while men have been shown to use it for more practical purposes (Muscanell & Guadagno, 2011). In regards to the other portion of our study, teacher respondents were only recruited from the state of South Carolina, for feasibility purposes, and only 10 teachers responded to the interview invitation.

Education systems are ever changing, and there is room for further research in this area. Broadening the population of teachers to include those from multiple states, or even countries, could expand the knowledge of what is understood and what more information is needed regarding AS or HFA. This type of study could be conducted in primary schools, or may be more warranted in a college setting since more students with AS are

pursuing further education. Since the educational tool developed from this study is primarily for the use of pediatric genetic counselors to provide to families they see with a child who has a diagnosis of AS or HFA, more focus could be placed in the genetics arena to see how families with autism are satisfied with their genetics evaluation and the information they are given by counselors.

#### 2.6 Conclusions

The incidence of autism spectrum disorders has steadily increased in the general population over the past few decades. In turn, as knowledge about the etiology and genetics of autism continues to grow, more of these individuals are being referred for genetics evaluations. It is a genetic counselor's duty to provide information and resources to families that are seen for an evaluation, and commonly these families have concerns about their child's education. Individuals with AS are in a unique situation because, although they are typically intelligent and deserve to be enrolled in regular education classes, their social difficulties often ostracize them from the rest of their peers, and possibly even their teachers. The educational tool developed from this study is designed to aid in initiating contact between the parents of a student with AS and their The vast majority of teacher participants in this study agreed that teachers. communication with the parents of students with AS is an important component to the success of that student. However, a noticeable proportion of parents surveyed felt that it was difficult for them to communicate with their child's teachers. We hope that this study and the tool that came from it will be of utility for parents of a child with AS, as well as all high school teachers, who may very well come into a situation in which they are educating a student with AS, if they have not already. In addition, we hope it adds value to the repertoire of resources that pediatric genetic counselors can offer while counseling families with a child who has a diagnosis of AS or HFA.

#### **Chapter 3. Conclusions**

The incidence of autism spectrum disorders has steadily increased in the general population over the past few decades. In turn, as knowledge about the etiology and genetics of autism continues to grow, more of these individuals are being referred for genetics evaluations. It is a genetic counselor's duty to provide information and resources to families that are seen for an evaluation, and commonly these families have concerns about their child's education. Individuals with AS are in a unique situation because, although they are typically intelligent and deserve to be enrolled in regular education classes, their social difficulties often ostracize them from the rest of their peers, and possibly even their teachers. The educational tool developed from this study is designed to aid in initiating contact between the parents of a student with AS and their The vast majority of teacher participants in this study agreed that teachers. communication with the parents of students with AS is an important component to the success of that student. However, a noticeable proportion of parents surveyed felt that it was difficult for them to communicate with their child's teachers. We hope that this study and the tool that came from it will be of utility for parents of a child with AS, as well as all high school teachers, who may very well come into a situation in which they are educating a student with AS, if they have not already. In addition, we hope it adds value to the repertoire of resources that pediatric genetic counselors can offer while counseling families with a child who has a diagnosis of AS or HFA.

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#### **Appendix A:** Invitation Letter to Parent Participants

## Dear Potential Participant:

You are invited to participate in a graduate research study focusing on high school students diagnosed with Asperger syndrome. I am a graduate student in the genetic counseling program at the University of South Carolina School of Medicine. My research investigates parental satisfaction and anxiety in regards to their child's mainstreaming experience, as well as teacher perspectives on teaching a child with AS. The research involves surveying parents, as well as interviewing regular education teachers in public high schools.

The parent survey attempts to gauge the satisfaction and anxiety levels regarding the student's experiences with school and being mainstreamed into at least one regular education classroom. If you do not wish to answer a certain question, please skip that question and continue with the rest of the survey.

All responses gathered from the surveys will be kept anonymous and confidential. No identifying information will be collected. A separate portion of the survey may be completed with your name and email address in the event that you are interested in entering a prize drawing. It is not necessary that you provide this information. The results of this study might be published or presented at academic meetings; however, participants will not be identified.

Participation in this research survey allows you to enter a drawing to win a \$25 gift card to a local restaurant or store. You are eligible to enter the drawing whether or not the survey is completed. If you are chosen, this prize will be sent to you at a later date, after having collected all data. Your contact information will not be used for any other purposes beyond contacting you about the drawing prize if you have won. Your participation in this research is voluntary. By completing the survey, you are consenting that you have read and understand this information. At any time, you may withdraw from the study by not completing the survey.

Thank you for your time and consideration to participate in this survey. Your responses may help genetic counselors create more helpful education materials for individuals with Asperger syndrome or high-functioning autism. If you have any questions regarding this research, you may contact either myself or my faculty adviser, Richard Ferrante, Ph.D., using the contact information below. If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at (803)777-7095.

# Sincerely,

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## **Appendix B:** Invitation Letter to Teacher Participants

#### Dear Potential Participant:

You are invited to participate in a graduate research study focusing on high school students diagnosed with Asperger syndrome. I am a graduate student in the genetic counseling program at the University of South Carolina School of Medicine. My research investigates parental satisfaction and anxiety in regards to their child's school and mainstreaming experiences, as well as teacher perspectives on teaching a child with AS. The research involves surveying parents, as well as interviewing regular education teachers in South Carolina public high schools.

The teacher survey will be conducted in a 10-15 minute phone interview and will attempt to gather perspectives on interacting with students who are diagnosed with Asperger syndrome. In addition, the survey will aim to determine important information for parents to provide to schools in order for educators to provide better for these students. If you do not wish to answer a certain question, please ask to skip that question and continue with the rest of the survey.

All responses gathered from the surveys will be kept anonymous and confidential. We only ask for your name and phone number in order to conduct the interview, and in the event that you are interested in entering to win a prize drawing. The results of this study might be published or presented at academic meetings; however, participants and schools will not be identified.

Participation in this research survey allows you to enter a drawing to win a \$50 Amazon gift card. You are eligible to enter the drawing whether or not the survey is completed. If you are chosen, this prize will be sent to you at a later date, after all data has been collected. Your contact information will not be used for any other purposes than conducting the interview and sending you the drawing prize if you have won. Your participation in this research is voluntary. By completing the survey, you are consenting that you have read and understand this information. At any time, you may withdraw from the study by not completing the survey.

Thank you for your time and consideration to participate in this survey. Your responses may help genetic counselors provide better information to families with students diagnosed with Asperger syndrome or high-functioning autism in the future. If you have any questions regarding this research, you may contact either myself or my faculty adviser, Richard Ferrante, Ph.D., using the contact information below. If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at (803) 777-7095.

# Sincerely,

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# **Appendix C:** Parent Survey

Parental Satisfaction and Teacher Perspectives on the Mainstreaming of Students with Asperger Syndrome: An Educational Tool
Exit
29%
<b>≭</b> 1. Has your child been diagnosed with Asperger syndrome?
○ No
<b>★2.</b> Does your child attend public high school?
○ Yes
○ No
<b>★</b> 3. Is your child enrolled in a regular education classroom for at least one class per day?
Yes
□ No
Prov. Next

			43	<b>%</b>
Please read each of toward that statement	of the following statemer ent.	nts and choose the ar	nswer that best descr	ibes your feelings
1. The teachers at	school fulfill my child'	s educational need	s	
Strongly disagree	Disagree	Undecided	Agree	Strongly agree
0	0	0	0	0
		_		
	ith my child's school e	_		
Strongly disagree	Disagree	Undecided	Agree	Strongly agree
0	0	0	0	0
3. My child tells m	e about the things he/s	she is doing with frie	ends at school	
Strongly disagree	Disagree	Undecided	Agree	Strongly agree
0	0	0	0	0
4. The teachers at	school do not suppor	t my child's emotion	nal needs	
Strongly disagree	Disagree	Undecided	Agree	Strongly agree
0			0	0
5. It is difficult for	me to communicate cle	early with my child's	teachers	
Strongly disagree	Disagree	Undecided	Agree	Strongly agree
0	0	0	0	0
6. I am satisfied w	ith how the teachers er	ncourage my child to	o learn	
Strongly disagree	Disagree	Undecided	Agree	Strongly agree
0	0	0	0	0
7 Marchild compl	aina ahaut bau ba/aha	in twented at each cal	h., other stratents	
-	ains about how he/she	Undecided	_	Otronoli, como
Strongly disagree	Disagree	Ondecided	Agree	Strongly agree
8 Teachers do no	ot understand my child	e nereonality		
Strongly disagree	Disagree	Undecided	Agree	Strongly agree
Ottorigiy disagree	Disagree	Olideolided	Agree	Citoligiy agree
9. My child's scho	ol does a good job of r	managing students	during class time	
Strongly disagree	Disagree	Undecided	Agree	Strongly agree
0	0	0	0	0
10. My child comp	lains about how he/sh	e is treated by the te	achers at school	
Strongly disagree	Disagree	Undecided	Agree	Strongly agree
0	0	0	0	0
		Prev Next		

5
---

Read each statement and select the appropriate response to indicate how you feel generally, most days of the week. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

1. I feel calm			
Not at all	A little	Somewhat	Very much so
0	0	0	0
2. I feel secure			
Not at all	A little	Somewhat	Very much so
0	0	0	0
3. I feel tense			
Not at all	A little	Somewhat	Very much so
O	0	0	0
4. I feel strained			
Not at all	A little	Somewhat	Very much so
0	0	0	0
5. I feel at ease			
Not at all	A little	Somewhat	Very much so
0	0	0	O
6. I feel upset			
Not at all	A little	Somewhat	Very much so
0	0	0	$\bigcirc$
7. I am presently worrying	over possible misfortu	unes	
Not at all	A little	Somewhat	Very much so
0	0	0	0
8. I feel satisfied			
Not at all	A little	Somewhat	Very much so
0	0	0	0
9. I feel frightened			
Not at all	A little	Somewhat	Very much so
0	0	0	0
10. I feel uncomfortable			
Not at all	A little	Somewhat	Very much so
0	0	0	0
11. I feel self confident			
Not at all	A little	Somewhat	Very much so

12. I feel nervous			
Not at all	A little	Somewhat	Very much so
0	0	0	0
13. I feel jittery			
Not at all	A little	Somewhat	Very much so
O	0	O	0
14. I feel indecisive			
Not at all	A little	Somewhat	Very much so
	O	O	O O
15. I am relaxed			
Not at all	A little	Somewhat	Very much so
0	0	0	0
40 15-1			
16. I feel content			
Not at all	A little	Somewhat	Very much so
O	0	O	0
17. I am worried			
	A 15441-	0	Managarah an
Not at all	A little	Somewhat	Very much so
O	0	0	0
18. I feel confused			
Not at all	A little	Somewhat	Very much so
O O	A little	O	C C
	0		
19. I feel steady			
Not at all	A little	Somewhat	Very much so
0	0	0	0
20. I feel pleasant			
Not at all	A little	Somewhat	Very much so
0	0	0	0
	Prev	Next	

	71%

Now, read each statement and select the appropriate response to indicate how you feel when thinking about your child's school experience. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your feelings best.

1. I feel calm			
Not at all	A little	Somewhat	Very much so
0	0	0	0
2. I feel secure			
Not at all	A little	Somewhat	Very much so
0	0	0	0
3. I feel tense			
Not at all	A little	Somewhat	Very much so
O	O	O	O
4. I feel strained			
Not at all	A little	Somewhat	Very much so
0	0	0	0
5. I feel at ease			
Not at all	A little	Somewhat	Very much so
Not at all	A little	Somewhat	very much so
O		O	O
6. I feel upset			
Not at all	A little	Somewhat	Very much so
0	0	0	0
7. I am presently worrying	over nossible misforti	ines	
Not at all	A little	Somewhat	Very much so
0	0	0	0
8. I feel satisfied			
Not at all	A little	Somewhat	Very much so
0	0	0	0
9. I feel frightened			
Not at all	A little	Somewhat	Very much so
0	0	0	0
10. I feel uncomfortable			
Not at all	A little	Somewhat	Very much so
O	O	0	O
11. I feel self confident			
Not at all	A little	Somewhat	Very much so
0	0	0	0

12. I feel nervous			
Not at all	A little	Somewhat	Very much so
0	0	0	0
13. I feel jittery			
Not at all	A little	Somewhat	Very much so
0	0	0	0
14. I feel indecisive			
Not at all	A little	Somewhat	Very much so
Not at all			Very much so
0	O	0	
45 Laws released			
15. I am relaxed	A 11441-	0	V
Not at all	A little	Somewhat	Very much so
0	0	0	0
16. I feel content			
Not at all	A little	Somewhat	Very much so
0	0	0	
17. I am worried			
Not at all	A little	Somewhat	Very much so
0	0	0	0
18. I feel confused			
Not at all	A little	Somewhat	Very much so
0	0	0	0
19. I feel steady			
Not at all	A little	Somewhat	Very much so
0	0	0	0
20. I feel pleasant			
Not at all	A little	Somewhat	Very much so
0	0	0	0
	Prev	Next	

The infor	information gathered on this page is for research purposes only and will not be linked to any identifiable mation. If you do not feel comfortable answering a question, you may leave it blank.
1. Aı	re you male or female?
0	Male
0	Female
2. ls	your child male or female?
	Male
0	Female
3. W	hat is your child's class standing?
	Freshman
	Sophomore
	Junior
0	Senior
-	oproximately how many times did you meet or speak with your child's teacher(s) in the last ool year?
	Never
	1-3 times
	4-7 times
	8+ times
5. W	hat is your annual household income?
	Less than \$12,000
	\$12,001 to \$30,000
	\$30,001 to \$50,000
	\$50,001 to \$100,000
	More than \$100,000
6. W	hat is your highest level of schooling?
	Did not finish high school
	Completed high school or GED
	Some college education
	Associate's degree
	Bachelor's degree
	College beyond Bachelor's degree
7. W	hat is your marital status?
	Single, never married
	Married
	Separated
	Divorced
	Widowed

86%

Next

Prev

[					100%		
address below. Th	sted in entering the d	linked to an	y of the previ	ous answe	rs you p	provided and wi	
be used only to pro survey!	ovide you with the gi	ft card if yo	u are the winn	er. Thank y	ou for t	taking our	
		//					
		Prev	Done				

## **Appendix D:** Teacher Qualitative Survey

- 1. What subject do you teach?
- 2. What classes do you teach? (i.e. freshmen, sophomores, juniors, seniors)
- 3. When you think of Asperger syndrome, what comes to mind?
- 4. About how many students with AS have you taught in your career that you are aware of?
  - If answer to this question is no students, skip to Question 6
- 5. If you have had experiences interacting with students with AS, how have your overall experiences been with interacting with these students in class and out of class?
- 6. Describe to me some of the challenges you have had (believe you would have) with a class that includes a student with AS.
- 7. What kinds of support have you received (do you believe you would receive) from other teachers or your administration when you have a student with AS in your class?
- 8. What kinds of interaction would you want with the parents of a student with AS?
- 9. What kinds of information would you want from parents of students with AS in order to provide better for the student?
- \*\* If participant has never taught a student with AS, questions 6 and 7 would be hypothetical

### **Appendix E: Teacher Interview Transcriptions**

### Participant 1

Answer 1: Drama, broadcast, theater

Answer 2: I teach a mixture of all grades.

Answer 3: Well, I think mostly I've had students who have trouble fitting in socially. And they get kind of fixated on one thing and it's really hard to dissuade them from that one line of thinking.

Answer 4: Probably in the last five years or so, probably three.

Answer 5: They've been really positive. I just, I had one student who was in a broadcasting class who was very fixated on providing readings from the bible on our broadcast and I had to... I explained to him that because we are a public school that we are not at liberty to do that and he... I thought he understood and then it showed up again on the announcements, I was like ahhh. He was very focused on that and that really wasn't like a bad, he was not being... he was not disobeying. He was just focused on that. He insisted that we do that.

Answer 6: I think mostly since the syndrome isn't, I mean it's not like kids understand, other kids, understand the syndrome. And sometimes they're not readily accepting of students with it, but I had one student, I think it was 2 years ago, you know, that the other kids thought he was kind of weird and didn't quite understand, you know, what was the matter or how to deal with him. He ended up being in our talent show and sang a number from "Fiddler on the Roof" and it was fabulous. And the other kids just, kind of, that just helped them to accept him in a different way. It just blew people out of their seats, amazing.

Answer 7: Our teachers, like our special ed teachers, have case loads and then we often had a speech therapist that worked with one of the kids with AS, and they both were, you know, in very frequent communication and checking on the progress of the students and they were also a good resource for explaining things to these students that may be in a different way than how I had.

Answer 8: Well, I actually got to know parents of 2 of the students pretty well, we would talk by phone or email. And the other young man we had him helping with the musical one year so I go to know his grandmother and met his mom and stuff. We had constant communication, but just being able to call them, or probably more accessible is the internet, and sending emails just to check up and that kind of thing.

Answer 9: Well, I think just for help as far as strategies of how to deal with different situations. Once we had one student who saw from the window that the EMTs were here to pick up a student who had become ill and he became very anxious and in a case like that talking to his mom and explaining what had happened and then she could give me some further insight as to how they dealt with him best in those situations.

#### Participant 2

Answer 1: I teach biology regular and honors biology.

Answer 2: I have all freshmen this year.

Answer 3: Generally, I guess children that experience... social issues. They don't know how to interact with their peers or they're kind of standoffish and they can be very bright. Maybe not in all their subjects, but they can be very bright and they don't know how to socially get along in the classroom.

Answer 4: I would say probably five.

Answer 5: For the most part they have been very good. Like I said, academically they usually do fairly well. Hmm, always have to work on social things. Some of them you know don't like a pat on the back, so I make sure I don't do that. I learned very quickly especially with one that I had everything was very literal. So, if I put on the board that we were going to do something for 15 minutes and we were going to be finished at 8:45, he was basically freaking out at 8:47 if we hadn't finished it. So, I learned very quickly in that class not to put time limits on things and nothing was really ever as concrete maybe. It was in my mind but I didn't put that out there for the class because he couldn't handle if it deviated from that. Kind of like when I grouped kids, I would try to make sure they were placed in a group that had some people that were probably more understanding if they didn't get along as well or they didn't have the social skills. As well, I'd make sure they were in a group that would be as polite and nice as possible with that.

Answer 6: Again in the class with this young man, I actually ended up moving him. He was in a regular class, and so the kids in there weren't nearly as focused as he was. He was all academic focused and they would get off task or take more time than they thought they should or if I gave them a little more time than he thought it should take... he couldn't deal with that. But I eventually had to speak with his parents and get him moved to my honors class where those children were much more like-minded. They wanted to get their work done and wanted to strive and do well and his frustration level went down greatly when he was around at least academic peers that were like him. And then, socially I'd work with him on social cues like, "You can't say that, it's okay if they do this, the world isn't going to end." I wouldn't make light of it or make a joke of it, but I would just let him know that it wasn't maybe as serious as he thought it had to be. I would say things like sometimes I know it's hard but you have to let it go.

Answer 7: Not a whole lot. We usually... we'll get IEP paperwork or something of what the kids may have. I hate to say but often times it's kind of like on a need to know basis and you don't need to know anymore. So, not a whole lot of support.

Answer 8: I guess more background info from the parents if they have it to share.

Answer 9: I guess it would be nice to know from the parents... like because there are certain behaviors or tics, clues whatever that might set the kid off and then make sure I kind of walk around those. I would say or do something in class and then realize I caused the kid to be frustrated or they're distraught over something that was said or done that could have been easily avoided. Like even changing seats, if they can't change seats every unit like we do, they just stay where they are.

### Participant 3

Answer 1: Science, chemistry and astronomy

Answer 2: I teach all sophomores, juniors and seniors.

Answer 3: Students that mostly have difficulties in social situations... but usually they're very intelligent.

Answer 4: That I'm aware of? I'd say probably four.

Answer 5: I feel like the experiences have been good. They... it depends on the severity of the Asperger's, I've had some students where it was just a little bit of a social hindrance. I think all the students kind of knew there was something different about the student, but not enough to make them feel like they'd been isolated at all. I had one student that was severely affected and I really had to watch him a lot closer in situations involving the laboratory just to make sure everything was safe. But the rest of them, they were fine. Socially, I've had the gamut from students that would openly talk to me in the hallways and interact with me, and then I've had students that were very quiet and wanted their space and I could tell when I needed to approach them; they needed to have a distance between us.

Answer 6: I think that the challenges that I've had, you know, the severely affected student was just a safety issue in the lab and it was difficult for me to monitor them as well as keep them safe as well as keeping the rest of the students safe, so we got to a point where I spoke with administration and they were able to find an assistant so anytime we came to the lab and we were dealing with gas or anything else that was caustic they would send another teacher or an assistant in to help that student so that everybody was safe, so that's one thing that I've had to deal with. The other issues have just been more of making adjustments if we have group work to do, giving that person the time to either do group work or if they're not comfortable, they can work on their own. Because a lot of times I've noticed my students with Asperger's have difficulties working in a group. Just allowing them to do assignments of their own or however

they're most comfortable. And then the student that had issues with personal space, just, you know, smiling and trying to put them at ease. I've found that the more interactions we had the more comfortable and the closer I could get. It's just establishing that comfort level with the student.

Answer 7: Well, the first thing always is you get an IEP that lists the disability and it tells you ways to combat disability or ways to adjust your teaching style for that student. Where I am currently is very good about having personal meetings with the case manager and they would come down and give me specifics about this is the situations that we've seen and this is how we handle it. They've been really good about giving you preventative measures. But they always have things in place; this is what we need to do in case we're having an off day or we come into a problem. And just abiding by what they tell me to do. In the case where I had the student where I was concerned about the lab safety, they were very supportive of getting somebody in here so I could keep that person safe, as well as the rest of my students safe. Just knowing about it is half the battle. So, I kind of prepare myself and kind of know what I'm getting into.

Extra note: The other thing is, it wasn't part of the question, but my mom has taught special ed for like 34 years and so I'm very accustomed to hearing stories from her or asking her about things that I can do to help my students that have disabilities of any kind, so I kind of feel like I have her in my back pocket. I'm very open and aware of special needs and I don't mind having them in my classes, just as long as I have communication about what I need to do to help them.

Answer 8: Again, I always feel like establishing contact in the beginning is one of the most important things. Opening up that channel is good. Just a heads up, so and so is having a rough day today or we had something happen this weekend and I'm kind of concerned about it this week. Again, prevention I think. But then also just ability to get ahold of them via email or via phone if I really feel like I need to. And if they're concerned, always letting them know that I welcome any kind of contact whatsoever. Most of the times, it's really just answering your case manager here at school. But if the parent wants to come to school, that's great too. Just knowing how to get ahold of the parents when I need to.

Answer 9: Just some maybe, just a heads up or we found ways if we have issues this is what we use or this is how we handle certain situations. I mean, most of the time I feel like my experiences are very little I've had with Asperger's, it's just been a behavior issue every now and then and sometimes there's silent signals that parents use. Or other things that would just be beneficial in knowing as a teacher just so I can continue that so I don't have to set up my own routine, I can use something that somebody else has used.

Extra note: I think that students with Asperger's don't necessarily come with papers. We know that there are some out there with paperwork but we also know that there are probably some students that we have that may have this issue but they just haven't been diagnosed for whatever reason. It gives you tools that you can use with all of your students and help you with classroom management and help you with students that may

have some of these similar issues. So I think that's great, it's just knowledge. Just knowing that they're in there and knowing what you need to do help. And experience having those students and treating them equal to everybody else, and as a teacher your attitude towards them helps the students know how they need to respond as well.

## Participant 4

Answer 1: I teach sports medicine

Answer 2: Mine is split; sports medicine 1 is 10th, 11th, 12th and 2 is usually 11<sup>th</sup> and 12<sup>th</sup> graders.

Answer 3: Um, kind of like Down syndrome type child you know, kind of disease, it's kind of like that.

Answer 4: None.

Skip Question 5

Answer 6: Attention for that child. You know, being able to differentiate the instructions to make it relevant for them but also relevant for everyone else in the class. Being able to keep attention, from not only from them, but from other students in the class.

Answer 7: Absolutely, yes ma'am.

Answer 8: Well just like with every other kid, the more a parent is involved I think the better. We would always want to have conversations and parent visits and stuff like that. The more they're involved I feel like the more successful the child is going to be.

Answer 9: If there's a problem, how to calm a child down. Especially if they got something that's going to hold them back a little bit, or any triggers that they may have, ways that they learn best. That's not for Asperger's, that's for every kid you know. How are they going to learn best, how do you prevent them from having a break down or something like that.

# Participant 5

Answer 1: Academic support

Answer 2: I teach to all of them.

Answer 3: Autism, it's on the autistic spectrum.

Answer 4: I've had two Asperger's but an awful lot of autistic kids lately. So really, two.

Answer 5: Well, the Asperger's kid had a lot of problems, a whole lot of problems. The high functioning autistic I haven't had nearly the problems with but the Asperger's kid I have loads of problems with. Huge behavior problems, huge academic problems, emotional problems.

Answer 6: Challenges are the fact that they're, I'll just talk about the one I had, disorganized, bad at math, emotionally unstable, they're way behind in social development and that affects their class relationships and ability to work with other students. Their emotional problems greatly affect their ability to stay in class and actually remain in the school.

Answer 7: Well, I'm the one providing for it because I'm the special ed teacher, and it's my job to give the support. I didn't have any problem dealing with the student but he took 90% of my time, and I gave a lot of support to the teachers as far as removing him when he had meltdowns and taking care of social and emotional problems. And that particular student, he had threatened and hurt a lot of our students too, so it was a hard situation and took a lot of time.

Answer 8: I would want them to be on the same team and be concerned about the child, so that we could work together to keep continuity, to minimize things and to minimize problems.

Answer 9: I think, examples of problems that Asperger's students would have. I think what I want parents to know is that teachers are their friends and special ed teachers, we're there to help them and to work together as a team. And too many times meetings turn out, particularly with something like autism, they turn out adversarial and they really shouldn't be because teachers in general want the best thing for their students just like parents want their children. That would be #1 is that the IEP is obtained, and that's something that a lot of parents don't understand. And I think autistic parents are notorious litigators and I think that they need to know that we're there to help them. I think that sometimes what I saw is the same characteristics in the parents. The parents of autistic kids really have no social skills, and I think parents see everything from the child's perspective and certainly the school needs to be safe for everybody. But then if your kid is threatening to kill somebody, you need to take it seriously too. All the kids count, not just the special ed ones. I know that's an odd thing coming from a special ed teacher, but I don't want any child to be victimized – our kids or other kids. And this particular student that I had threatened to kill people on a regular basis, he had a hit list of kids. And his parents were very adversarial and it would have worked a lot better if we all could have worked as a team. And I think that's what parents, so many times, the autistic parent community is so strong, and I get the impression from even from my friends that have autistic kids, it's like they're the only people that count and that's just difficult for me. And I think just that they just need to know that their student's going have bad days just because of their disability. And that they have a lot of potential and they have a lot of strengths too, particularly with autism and high functioning autistic kids have an incredible memory. They're like little human encyclopedias and they see things in a really interesting way and there are a lot of good things that will come from these kids too.

### Participant 6

Answer 1: Special education, resource

Answer 2: I have students from all grades.

Answer 3: Intelligence, capable, difficulties with socialization, bright, talkative.

Answer 4: Two.

Answer 5: They have been eager to learn and, like I said, bright, able to catch onto to concepts fairly quickly. But, they often needed teaching methods that were different from the other students.

Answer 6: Generally they were not as interested in participating in group activities, and in my classroom most everything was done in groups, whether it was pairs or small groups. So, just adapting different activities to be more individual for them. And, they also often did not understand certain social cues and certain social situations that may occur in a classroom. Such as, just little poking, teasing from classmates that could go on between any of the students. They tended to not really understand or pick up, or they would become upset with stuff like that, so just I guess, socially.

Answer 7: There are some wonderful exploratory teachers teaching PE and art and such that were very open to having my students in their classroom and worked really well with them to include them in all of the activities going on. Administration wise, I've been supported in the sense that the administrators are well aware of my students and their needs and they're able to back me up if there's a discipline issue. We have to handle discipline differently that with students in the general ed setting, so they've been sensitive to that, they've been sensitive to meeting the parents with students who might be having issues when they're in a regular ed classroom. They've been very supportive in that way. There have been some teachers who haven't been as excited about having my children in their classrooms but they slowly but surely have come around to learning how to adapt lessons and stuff to be able to include my students in what they're doing.

Answer 8: I would prefer phone calls just because it's instant... you instantly get an answer or reply. You can tell... you can sense tone of voice and stuff like that. But I've found that sometimes email is just faster and it works better, they're able to email from work or from their phone. So, really any kind of interaction is positive for me because some parents can be kind of standoffish and don't take as much interest in their child's education, but if they're willing to email or talk on the phone, then I'll interact however is best for them. And face to face is good to, I always like having face to face meetings with my... with the parents of my students as often as possible. And I like to get them

involved in the classroom as well; coming in for Special Olympics or coming in for different projects that we do. And they're generally open to being a part of the classroom.

Answer 9: Well clearly, medical history, behavioral history before coming to me, I'd like to know what they want for their child, if they want their child to have more of an academic education or more of a skills based/life skills/functional curriculum type education. What goals they have for their child in the future so that I can do my best to help them attain that within my given abilities, within the classroom.

### Participant 7

Answer 1: I teach kind of a little bit of everything.

Answer 2: Well, our kids aren't really split up by grade level. The program that I teach in is the occupational program so it is for students who are not earning a diploma. So I teach, I teach a math block and it's got actually all grade levels in it, we group them by what their skill level is.

Answer 3: I guess social issues. Just having trouble interacting socially and knowing social appropriateness.

Answer 4: That have been officially diagnosed? None. None that have been officially diagnosed. I've got a couple now that I'm pretty sure are somewhere on the spectrum and probably are.

Answer 5: I think they've been good. It's kind of interesting to observe the student that I have right now that hasn't necessarily been officially diagnosed definitely has tendencies and things like that, so it's been interesting to kind of observe and see the different tendencies that he exhibits and how he does gets along with his peers and that kind of thing. But, I haven't had any negative experiences.

Answer 6: I think one of the biggest problems would be getting the other students to accept. In my program, because there are, you know, all the students have a disability, when one person is a little different they don't think a whole lot about it. But I know when you're in a general ed classroom sometimes the differences, especially with Asperger's, because a lot of it is social issues, it can be hard to kind of explain and for other students to be accepting and take advantage of the teachable moments that you might have. With special ed students, it's a lot easier to take advantage of the teachable moments.

Answer 7: I mean there's been the resource at the district office as far as people that may have more experience than I, maybe ask their opinions on or advice on. Like the psychologist that's here at school just to kind of get input. Am I doing this correctly or am I doing this appropriately? What do you think would be a good idea and how to address it?

Answer 8: I would prefer parents coming in to meet or phone calls because I feel like in email you lose so much in the translation as far as the tone and things like that. So, I wouldn't want them to feel like in our discussion that any questions I was asking would be accusatory or negative in any way. And I would want them to understand that whatever responses they were getting, maybe about typical behaviors or the way they handle things, that they would understand that I was really truly listening. To get parental support, they've got to know that you're listening and that you're interested in what's going on.

Answer 9: I think I would really want to know what kinds of things they exhibit at home, have they found things that have worked or what has been successful in the past? I also really think it's important to know from the parents what are the goals they have for their child. If the parent has unrealistic goals or things like that for their own child then it's hard to maybe help the child reach those goals. As a teacher, you want to help facilitate and support the goals of the parent and the student. So, to know where they see their child in the next 5-10 years and what can I do to help support whatever they're doing at home to get the child to be successful.

### Participant 8

Answer 1: I teach chemistry and AP environmental science.

Answer 2: All of them.

Answer 3: Awkwardness, loner, inability to relate to peers.

Answer 4: Only one for sure, but probably three that I strongly suspect and I only suspect it because my niece has Asperger's and so they resembled her.

Answer 5: They've been fine, they've been good. I feel like I knew only because of personal experience what I was dealing with. So I kind of felt like I knew how to handle those kids.

Answer 6: Ironically protecting that student's feeling from harmful things other kids say. The ironic thing is that it bothers me a whole lot more than it bothers the kid with Asperger's, how rude and cruel other kids can be. Another challenge I had with the one particular kid I'm thinking of, he didn't relate to any of his peers so he thought that he and I were more on a social level. So that when there was group work or a little bit of down time he would seek me out, like he should have sought out a peer. That was awkward; it was awkward for everybody in the room. When a discussion came up, like what do you think of this, he had a hard time being succinct in his thoughts. He would just go on and on and on and on.

Answer 7: I don't know of any resources that administration has. Probably the best support would just be informal conversations with other teachers.

Answer 8: Emails.

Answer 9: I would want to know how sensitive he was and how much he was bothered by others. Some kids are really bothered by snide comments and general social shunning and some kids do not care. So that would be my main question: does your kid come home from school upset about not having any friends? The big concern I had with the child I had last year was that he would just get so overwhelmed. If he didn't understand something, instead of raising his hand and asking for help, he would almost just explode. So, that would have been helpful to know that it wasn't a behavioral issue really, I mean it is, but it's not. It just would have been helpful to know that I cannot overload this kid; it is one thing at a time.

### Participant 9

Answer 1: English

Answer 2: Sophomores and juniors.

Answer 3: A student by the name of Xxxx actually comes to mind. He has a brother who is autistic and he and his other brother have Asperger's and, you know, kind of what I would notice about him is that, you know, socially he just wasn't like the other kids; a little different.

Answer 4: Probably, that I'm aware of, probably only like three or four.

Answer 5: Not that bad. You know, because, truthfully, the kids I've taught who have this diagnosis were actually in honors classes. So, you know, as far as no disciplinary issues with them really and it was one in particular. Sometimes you needed to be somewhere and he wanted to stay and talk and possibly talk about something that has no relevance whatsoever to you. It's like, how do I politely get him to go on.

Answer 6: With him in particular, you'd have to be very careful in discussions because what he might say might be offensive to other people.

Answer 7: I don't think so much that I've ever needed support with the particular kids that I've had, but we are very fortunate that we have a psychologist readily available if we need somebody. One of our administrators works very closely with any of our special needs students and everything, so they're very aware of any diagnosis that a kid might have and you can always go to them, too.

Answer 8: Those particular kids? We never wanted to see the parents but they were there all the time. Not so much with the kid I've had but the one that's there now, his mother is there every time I turn around. We can't wait for this kid to graduate. I would say face to face, phone calls, something like that.

Answer 9: I think I'd want to know the diagnosis, you know, and now they're better at letting you know this, but I can remember having students with different issues and having no clue, I mean, I had a kid one time that he kept coming to class late so when I'd take him outside to have a word about it, the kid is trying to almost crawl in to the lockers. So I was thinking great, I have jumped an MR kid and I had no clue. So, they're better at letting us know that. But, in some cases, it would be better to have some specific information. I had a kid who lost it in the classroom and fortunately there was a principal in there who was working on one of my computers and they were working in groups and this one kid lost it and the principal took him out and then later when the principal came back in he said, "Were you not aware that this could happen?" And I said no, nobody has told me anything. So, if there is a situation like that it is good to know. Even if it's to the point of he doesn't need to be around particular students then you make sure that he's sitting somewhere else or there's something topics that you don't broach if you realize that it's going to be a trigger.

## Participant 10

Answer 1: Intro biology, physical science.

Answer 2: Mostly freshmen and sophomores.

Answer 3: High level of intelligence... routinized, like, you know, needs structure, doesn't do well with change.

Answer 4: Three or four.

Answer 5: They've been good... never had any kind of issues with them. I taught two at (SC high school) and they were very focused on their education, very focused on being successful. But I do remember kind of a dislike... they didn't like the bells, they didn't like assemblies, they didn't really like being out in the halls much during class change.

Answer 6: Differentiating to include them and... just making sure they're focused and they're getting the support they need and the structure they need.

Answer 7: Plenty. We always have a psychologist and we always meet with them and get their input. Sometimes we communicate with doctors on certain needs and certain triggers that can be harmful.

Answer 8: Phone calls or parents coming in to meet.

Answer 9: Their likes or dislikes, things that make them upset, their past performance in school.