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GRADUATED STUDENTS WITH AUTISM SPECTRUM DISORDERS
AND THEIR PARENTS: LIVED EXPERIENCES IN PUBLIC HIGH SCHOOL

by

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A dissertation submitted in partial fulfillment of the requirements
for the degree of Doctor of Education
in the College of Education
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Orlando, Florida

Spring Term
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ABSTRACT

Graduated Students with Autism Spectrum Disorders and Their Parents: Lived Experiences in Public High Schools

With a dramatic increase in the prevalence of students with autism spectrum disorders (ASD), including those with high-functioning autism and Asperger's syndrome, educators are challenged to meet the educational needs of a complex and widely diverse group of exceptional learners. The focus of this research was to gain insight into the experiences of the graduated student with autism and his/her parent(s) during the student's time in public school. This study had three research questions: 1) What were the lived experiences of students with ASD who graduated from an urban public high school in the southeast United States?; 2) What were the lived experiences of the parents of the graduated students with ASD?; and, 3) Were there common themes between the graduated students' lived experiences and the parent's lived experiences? Five graduated students and their parents were interviewed in this qualitative, phenomenological study. Explication of the interview data identified three themes for the graduated student group: a) challenges with learning due to having an ASD; b) difficulty making friends; and, c) involvement in their educational process. Four themes were present in the parent group: a) challenges with learning due to having an ASD; b) difficulty making friends; c) establishment of a relationship with the school; and, d) preparation for post-secondary experiences. The graduated student group agreed with the parent group on 16 of the 20 interview questions. Responses for each graduated student were compared to the responses of his/her own parent(s). Recommendations were made for future research.

To the graduated students and their families: I dedicate this work to you. May this be an accurate reflection of your school experiences.

To my students: you are the reason why I wanted to know more.

To my parents, who always wanted me to be a doctor...

To my amazing children and grandchildren- I love you beyond words!

To my husband Tom, forever and eternity...

Matthew 19:26 With God, all things are possible.

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CHAPTER 1

INTRODUCTION TO THE STUDY

Characterized by deficits in social development, communication, and repetitive behaviors or interests, autism is by all accounts an intriguing and complex disorder (American Psychiatric Association, 2000). During the past decade, prevalence rates of Autism Spectrum Disorders (ASD) have had a striking increase of more than 1100% (U.S. Department of Education, 2002). Current research indicates that prevalence rates of individuals with an ASD are now as high as one in every 110 (CDC, 2009). The task of meeting the diverse curricular needs of students with ASD continually challenges public school systems (Postal, 2009). Evidence suggests interactions between parents of students with ASD and educational professionals are less than positive—even adversarial (Stoner, Bock, Thompson, Angell, Heyl, & Crowley, 2005). Since its identification as a separate disability category in the 1990 reauthorization of the Individuals with Disabilities Education Act, a dramatic increase in litigation regarding education of students with ASD has been reported. Tension between parents of students with ASD and the educational system may be the underpinning of this increase in litigation (Yell, Katsiyannis, Drasgow, & Herbst, 2003). In some instances, school districts have adopted specific educational practices to avoid litigation (Mandlawitz, 2002).

Students with ASD report difficulties with teachers and peers in the educational setting (Humphrey & Lewis 2008). Regardless of academic ability, students with ASD share common difficulties: a) making sense of the world, and b) experiencing ridicule and bullying by their peers (Humphrey, 2008). Devaney (2009) acknowledges the challenge of school districts to meet the academic needs of students while addressing students' social deficits. Devaney

recommends school districts engage parents and families of children with autism by treating them as equal partners in the process. MacLeod and Johnstone (2007) indicate that first-hand accounts of the experience of students with ASD have the potential to enhance and guide actual practice. Effective educational practices, policies, and programs are needed for a greatly increasing population of students in the public school system (Billington, 2006; Devaney, 2009; Myers, 2009; Newman, 2007; Postal, 2009; Simpson, deBoer-Ott, & Smith-Myles, 2003; Stoner, et al., 2005).

Relevance and Significance

This research contributes to the body of literature describing the unique academic, social, and personal experiences of students with ASD who have graduated from a large urban public high school since 2005. A dramatic increase in prevalence of students with ASD in the public schools has been well documented (U.S. Dept. of Ed., 2006). Additionally, a greater volume of cases has appeared in the United States judicial system regarding provision of appropriate educational opportunities and interventions for students with ASD.

This research will identify common themes of the students' and parents' lived experiences with the public school system. Awareness of the subjects' experiences may suggest programmatic adjustments which could better address the needs of students with ASD. Parents' lived experiences may also suggest approaches for educators to collaborate effectively with their students' families. As with qualitative research done by Billington, McNally and McNally (2000), this research attempts to erode the boundaries between experience and expertise, theory and practice. An analysis of responses from the students and parents may suggest areas of

support to provide desired outcomes for both the students and their families (Powers, Geenen, & Powers, 2009). With a multiple-participant phenomenological research design, the strength of any inference made increases when factors recur with more than one participant (Lester, 1999). Therefore, this multiple-participant research study will draw its strength from the views of the following participant groups: a) student to student; b) parent to parent; and, c) student to parent.

Research Questions

This study investigated the lived experiences of young adults with ASD, including those diagnosed with High Functioning Autism (HFA) or Asperger's Syndrome (AS), who graduated from a large urban public high school in the southeast United States since June 2005. The lived experiences of the parents were also documented. The increased prevalence of autism creates a strain on the educational systems trying to establish best-practice standards. Due to the complex and diverse needs of students with ASD, engaging parents and families in a team approach is recommended (Devaney, 2009). The research questions this study examined three areas of experiences:

- 1) What are the lived experiences of students with ASD who have graduated from a large urban public high school in the southeast United States?
- 2) What are the lived experiences of the parents of the graduated students with ASD in the urban public school setting?
- 3) Are there common themes between the graduated students' lived experiences and the parents' lived experiences?

Students' Lived Experiences

In order to understand the lived experiences of students with ASD, it is necessary to pay attention to their narratives and personal experiences (Connors & Stalker, 2007). Collecting the students' perspectives of their educational experiences in public school may help with program development for students with ASD. Additionally, collection of information from the students' perspectives may assist school administrators and ASD support personnel when making classroom placement decisions for students with on the higher end of the autism spectrum (Humphrey & Lewis, 2008).

Parents' Lived Experiences

The IDEA Amendments of 1997 expanded the involvement of parents in their child's special education process. Fostering parental involvement in their child's educational programming is considered a critical element associated with successful outcomes for children with ASD (Sansosti, Powell-Smith, & Cowan, 2010). On the other hand, several factors were identified by Lake and Billingsley (2000) which either escalated or de-escalated parent-school conflict in special education. These factors included discrepant views of : a) the child's needs; b) knowledge of special education; c) service delivery; d) constraints; e) valuation; f) reciprocal power; g) communication; and, h) trust. Parsons, Lewis, and Ellins (2009) determined that parents of children with ASD find it disproportionately more difficult to obtain appropriate education provisions for their children when compared to parents of children with other disabilities. In studies with parents of children with ASD, researchers found that acquiring

insider accounts through direct communication and interaction with parents may provide professionals with a valuable source of information when creating services and developing practices. (Billington, 2000; Billington, McNally, & McNally, 2006; Stoner, et al., 2005).

Questions from the study by Stoner, et al. included:

- Describe the services your child received in the school system.
- Tell me about the communication between you and the school.
- Do you feel like you are a part of a team with the educators?
- Describe your relationship with your child's teacher.
- Describe your relationship with the administration.

Interviewing those who best understand the child with ASD may provide insight to educational professionals, resulting in improved outcomes for students with ASD (Sansosti, Powell-Smith, & Cowan, 2010). Collaborative relationships between families and educational professionals are related to increased student achievement. Additionally, fewer discipline problems for students with ASD are observed when a collaborative relationship between school and home has been established (Wilkinson, 2005).

Three guide questions with five to eight subsidiary questions were asked of the research subjects. The three Guide questions were:

- *Question 1*
 - *Student Question: What was your academic experience as a student in an urban public high school?*

- *Parent Question: What was your academic experience as the parent of a student with an autism spectrum disorder in an urban public high school?*
- *Question 2*
 - *Student Question: What was your social experience as a student in an urban public high school?*
 - *Parent Question: What was your child's social experience as a student in an urban public high school?*
- *Question 3*
 - *Student Question: What do you remember about your involvement, and your parent(s)' involvement, in your school experience?*
 - *Parent Question: What do you remember about your involvement, and your child's involvement, in his/her school experience?*

A complete listing of the guide and subsidiary interview questions for graduated students and for parents can be found in Appendix B and Appendix C.

Comparison of Graduated Student and Parent Responses

Research documents the lived experiences of students with ASD (Humphrey & Lewis, 2008), as well as the lived experiences of parents of children with ASD (Stoner, et al., 2005). To date, scant information has been published indicating the commonalities among the lived experiences of students with ASD relative to their parents' experiences. It is possible, if not likely, that students and parents may, at times, have dissimilar experiences, expectations, and

goals (Powers, Geenen, & Powers, 2009). Are students generally in agreement with their parents about their public school experience? Do students wish for an outcome different from their parents? Do students and parents communicate with each other in such a way as to have a unified outcome objective? The comparison of parent and student responses may assist educators and clinical personnel in minimizing potential conflict, especially in the process of transition planning (Powers, Geenen, & Powers). Recurring factors found in student and parent responses also provide support for best practices in program development (Devaney, 2009; Lester, 1999).

The Scope

This phenomenological study included five former students with ASD who graduated from an urban public high school in the southeast United States since 2005. An in-depth, retrospective interview was conducted with the students, as well as each student's parent(s). Interview questions focused on students' and parents' lived experiences pertaining to academic, social, and personal support while in the urban public school setting. Interview questions included subject's satisfaction with the adequacy of preparation for transition to post-high school settings. Other questions asked subjects to describe strategies that were most successful in helping students achieve personal goals. Finally, questions were asked to determine the level of agreement between the graduated student and his/her parent(s) in terms of academic and social experiences.

Definition of Terms

Terms used in this study are listed in alphabetical order, as follows:

Agreement: Interview questions in which two or more responses were similar were noted as *agreement*. In phenomenological research, the strength of inferences which can be made increases rapidly when factors recur with more than one participant (Lester, 1999). Conversely, *disagreement* is noted when a response is not shared by other participants.

Asperger's Syndrome(AS): A neuropsychiatric disorder on the autism spectrum characterized by significant impairment in social interaction and development of restricted patterns of behavior or interests (VanBergeijk, Klin, & Volkmar, 2008). AS differs from autism disorder in that AS specifically excludes cognitive and language delays (Thede & Coolidge, 2007).

Autism Spectrum Disorder (ASD): A group of developmental disabilities usually detected in children before the age of three years. Not everyone with an ASD has the same challenges, but typically communication, social skills, narrow areas of interest, and unusual or repetitive patterns of behavior are observed. Cognitive ability of ASD ranges from severely intellectually disabled to intellectually gifted. In education, ASD is the term used to identify students with disabilities anywhere on the autism spectrum, from very low functioning to very high functioning and Asperger's syndrome (CDC, 2009). Current definition of ASD according to the Florida Department of Education includes the following characteristics: a) an uneven developmental profile across the domains of language, social interaction, adaptive behavior, and/or cognitive skills; b) An impairment in social interaction evidenced by delayed, absent, or atypical ability to relate to people or the environment; c) an impairment in verbal and/or

nonverbal language or social communication skills; and, d) restricted repetitive and/or stereotyped patterns of behavior, interests, or activities (Florida Department of Education, 2007).

Cohen's Kappa: Cohen's *Kappa* is an measure of inter-rater reliability that may be used to measure the level of agreement between two sets of ratings or scores. Cohen's *kappa* is a preferred measure of agreement over a simple percentage of agreement because Cohen's *kappa* takes into account the possibility of scoring at random. Correlations greater than .70 are considered good inter-rater agreement for researcher purposes (Wood, 2007).

Epoche: a process in phenomenological research in which the researcher's meanings and interpretation of the research topic are intentionally set aside, allowing the experience of the participant to be known (Groenewald, 2004).

Expert Focus Group: A qualitative research technique in which selected experts review and recommend questions for study based on the expert's subject matter knowledge (Czaja & Blair, 2005).

Explicitation: Explicitation is a term used in phenomenological research, and is preferred to the term *data analysis*. Explicitation investigates the phenomena in the context of the whole, rather than breaking the phenomena down into subparts, as in data analysis (Groenewald, 2004).

Free Appropriate Public Education (FAPE): FAPE is one of the major principles of the Individuals with Disabilities Education Act (IDEA), Section 504 legislation. FAPE provides educational programs and services to meet the needs of students with disabilities at no cost to the student or family (U.S. Department of Education Office for Civil Rights, 2007).

High Functioning Autism (HFA): Autism is characterized by qualitative impairment in social interaction, communication, and restricted interests or repetitive behaviors. The term

“high functioning autism ” is often used to describe a subgroup on the autism spectrum who have an intelligence quotient (IQ) greater than 70 (Tsatsanis, 2004).

High Functioning Autism / Asperger’s Syndrome (HFA/AS): A term used to denote individuals who have either Asperger’s syndrome (AS) or high-functioning autism (HFA). For purpose of this study, no distinction is made between research participants who have AS and those who are HFA; they are considered collectively as ASD (Tsatsanis, Foley, & Donehower, 2004).

High School Graduate: A student who has completed the required course of study in order to obtain either a standard diploma or a special diploma is considered a high school graduate. In the state of Florida, both standard diploma and special diploma tracks have specific guidelines required to obtain a diploma. Students must have an unweighted grade point average of at least 2.0. In addition, students who receive a standard diploma must complete (with a passing grade), the required and elective courses, and pass the Florida Comprehensive Assessment Test (FCAT), or satisfy the requirements for obtaining a waiver (Student Progression Plan, 2009).

Least Restrictive Environment (LRE): Federal Individuals with Disabilities Education Act (IDEA) requires that children with disabilities be educated, to the maximum extent appropriate with children who are not disabled. This educational placement decision is made at the child’s Individual Education Plan (IEP) meeting (U.S. Department of Education, n.d.).

Lived Experiences: Lived experiences is a term used when describing phenomena with which the subject has direct experience. Lived experience contrasts with secondhand experience (Patton, 2002).

National Board Certified Teachers: Teachers who achieve National Board Certification have met rigorous standards through intensive study, expert evaluation, self-assessment and peer review. Twenty-five different subject areas are available for National Board Certification. The National Board Certified Teachers used in the expert focus group for this research have certification in the area of Exceptional Needs Specialist (National Board for Professional Teaching Standards, n.d.).

Neurotypical: Neurotypical is a term that is often used to describe one who is not on the autism spectrum (Larsen, 2007).

Outcome Objectives: Outcome objectives refers to the perceived goal of education from the perspective of the participant. For the purpose of this study, participants include the graduated student and the student's parents. Parents and students have the right to participate in educational and outcome objective determinations (Billington, 2006). The term *personal goals* may be considered synonymous.

Parents: For the purpose of this study, the term *parents* refers to either biological or adoptive caretakers of the students with ASD. IDEA mandates that parents of children with disabilities have a legal right to be involved in all aspects of their child's education; parental involvement is critical in providing effective educational experiences for children with disabilities (Stoner, et al., 2005).

Phenomenological Research: Phenomenological research strives to gain insight into the world of the study participants. Data are collected through in-depth interview. From these data, essential characteristics of the participants' experiences are clustered into themes (Fraenkl & Wallen, 2006).

Pulse SmartPen™: A SmartPen audio records conversations while simultaneously digitizing handwritten notes taken on Livescribe Paper Replay™ paper. The paper has microscopic dots on it, which synchronizes the audio recording with the written notes. By tapping the ink, the SmartPen replays the conversation from the exact moment the note was written. Audio recordings and written notes may also be synchronized to a computer (Livescribe.com, n.d.)

Refabrication: Refabrication is the reconstruction of a memory from bits and pieces of the truth. When stories are told and retold they are often embellished; eventually, the embellishment becomes part of the memory making it difficult to distinguish between detail facts and embellishment (Wolfe, 2001).

Section 504 Plan: A Section 504 Plan, or ‘504 Plan’ refers to a Civil Rights law which provides necessary accommodations and/or modifications for individuals with mental or physical impairments which substantially limits their participation in one or more major life activity. The modifications or accommodations are established so the individual with the 504 Plan has the same opportunity to perform at the same level as their peers. It differs from an IEP because it is not part of the Individuals with Disabilities Education Act (IDEA) legislation. (Mauro, n.d.)

Themes: Major ideas that help organize and categorize large amounts of descriptive information are referred to as themes (Fraenkel & Wallen, 2006).

Limitations

Language is often a challenge for students with ASD; therefore, this research included only the higher-functioning students with ASD. As such, this research will not attempt to make

generalizations for the entire ASD population. When a sample is drawn from one specific geographical area, e.g., from a large urban area in the southeast United States, generalization to students with ASD in other parts of the country may be limited. Questions in this research drew upon students' and parents' ability to recall lived experiences. There is a possibility that subjects may unintentionally omit important information. This omission of information may also affect the results of the research, thereby corrupting the ability to generalize information to the population of graduated students with ASD. Generalizations may be limited because the sample size is small; however, insight gleaned from the subjects' lived experiences may provide the basis for continued study of program strategies, thereby optimizing student success and reducing parental dissatisfaction.

Method of Organization

This research is presented in five chapters. Chapter 1 provides an introduction to the study including the research questions investigated, a clarification of terms to be used, a statement of the relevance and significance of the research, the scope of the research, and the barriers and limitations of the research.

Chapter 2 reviews selected literature on high functioning autism spectrum disorders. Research in the fields of parental rights, litigation, and phenomenological research will be included.

Chapter 3 outlines the methods and procedures that will be implemented to collect the data, and describes the way in which the data will be analyzed. Data from the interviews will be coded and interpreted for analysis.

Chapter 4 reviews the results of the data analysis. Theme commonalities found among the participant groups are presented: the essence of the students' experiences, the essence of the parents' experiences, and comparison of the students' and parents' experiences.

Chapter 5 provides a summary of the research findings and conclusions that may be drawn from these findings. A section on discussion of the results, recommendations for future practice, and suggestions for further research are also provided in this chapter.

Summary

Chapter 1, Introduction to the Research, provided an overview of this study. The relevance and significance of this study were presented, supported by documentation of the increased prevalence of students with ASD. The three research questions were introduced, and the three guide questions for the interviews were presented. A discussion of the scope of the research was followed by: a) the definition of terms used in the research; b) a statement of limitations of this research; and c) the method of organization used in this research.

CHAPTER 2

REVIEW OF THE LITERATURE

Autism spectrum disorder: a diagnosis that is a complex and powerfully emotive experience for parents (Avdi, Griffin, & Brough, 2000); a term that is baffling to many educators. ASD covers all levels of cognitive ability from profoundly mentally retarded to intellectually superior (Tsatsanis, 2004). The burgeoning prevalence of students with ASD in mainstream classrooms creates stress not only for educators, but for students with ASD and their parents as well (Leblanc, Richardson, & Burns, 2009; Sansosti, Powell-Smith, & Cowan, 2010).

Diagnostic Criteria of Autism and Autistic Subtypes

The term ‘autism spectrum disorder’ encompasses a range of disorders described in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR) in the pervasive developmental disorder category that includes Autistic Disorder and Asperger’s Syndrome (American Psychiatric Association, 2000). While different diagnostic criteria exist between Autistic Disorder and AS, no specific criteria exists in the *DSM-IV-TR* for high-functioning autism (HFA). The term HFA appears frequently in the literature, and researchers debate whether HFA and AS are the same, or different, disorders (Thede & Coolidge, 2007). Regardless of functioning level, *autism* is the term used for this specific disability category in the Individuals with Disabilities Education Act (NICHCY, 2009).

Low functioning autism is typically used in literature to describe those with an intelligence quotient (IQ) less than 70; HFA describes those with an IQ greater than 70. AS is a

term associated with those who are less impaired, more verbal, and older when diagnosed (Tsatsanis, 2004). Characterized by absent or mild intellectual impairment, individuals with AS have social deficits, and intact language which is often difficult to differentiate from other exceptionalities, including learning disabilities, psychiatric disorders, or other autism spectrum disorders (Barnhill, Hagiwara, Myles, & Simpson, 2000). Barnhill, et al., investigated the cognitive profiles of students with AS and determined that, similar to profiles of the general population, there was no significant difference in verbal intelligence quotient (VIQ) and performance intelligence quotient (PIQ) scores, which is discrepant from the profiles of student with non-verbal learning disabilities and ASD. When comparing frequency and intensity of repetitive behaviors of students with HFA and AS, Cuccaro, Nations, Brinkley, Abramson, Wright, Hall, Gilbert, and Pericak-Vance (2007) found no significant difference between the two groups. Research by Thede and Coolidge (2007) suggested some distinction between HFA and AS: children with AS were significantly more anxious than children with HFA. Regarding meaningful differences between HFA and AS, Cuccaro, et al., stated little difference exists, and differences that do exist are likely to be important in genetic and neurobiological studies. Sansosti, Powell-Smith, and Cowan (2010) stated that attending to the needs of children with HFA/AS is more important than trying to determine a specific diagnostic label.

Some of the confusion educators have about autism originates with a change in the concept of autism over recent decades (Wing & Potter, 2002). When first described, individuals with autism had low IQs, limited language, and bizarre behavior (Gold, 2000). Core deficits across the autism spectrum were mostly in the areas of reciprocal social interactions and repetitive behaviors (Wing & Gould, 1979). A deficit model seems to be the most utilized

approach by educational professionals. If the assessment focus is shifted from identifying deficits to recognizing abilities, targeted behavior takes on a vastly different meaning, and suggests a different approach in educating the child and supporting the family (Billington, McNally, & McNally, 2000).

While contemporary researchers often place HFA and AS at the mildest end of the autism spectrum, HFA and AS should not be regarded as a mild disorder (Sansosti, Powell-Smith, & Cowan, 2010). Severe challenges with social skills and behavior (Atwood, 2007), as well as pragmatic language (Landa, 2000) and affective disorders may compromise success in most environments (Tsatsanis, Foley, & Donehower, 2004). Price (2010) noted that many adolescents with AS or HFA emerge from high school having experienced years of bullying and social isolation. As a result, national statistics estimate that only six to 14 percent of adults with AS or HFA are competitively employed. For those who have post-secondary educational aspirations, colleges and universities are struggling to create effective interventions for the communication, social, independent living skills, and executive functioning challenges of the students with ASD (VanBergeijk, Klin, & Volkmar, 2008)

Current Prevalence of ASD

Most statistical reports indicate an increase in the prevalence of ASD. The U.S. Department of Education, Office of Special Education Programs tracks data on the number of children with disabilities receiving special education under Part B of the Individuals with Disabilities Education Act (IDEA). The prevalence of students served under the disability category of autism has grown from .66 percent of all students with disabilities, ages 6 – 21 in

1996, to 3.2 percent of all students with disabilities, ages 6 – 21 in 2005 (U.S. Department of Education, 2006). A report by the Autism and Developmental Disabilities Monitoring Network (ADDM) indicated that prevalence rates, in the surveillance year of 2006, of children aged eight years was approximately 1%, or one child in 110. ASD was reported to be more prevalent in males than females (approximately 1: 70 for males, and 1:315 for females). Comparing prevalence data from the previous surveillance year (2002) found that prevalence increased 60 percent among males and 48 percent among females (CDC, 2009). No other disability category has seen such a significant increase in prevalence rates (Newschaffer, Falb, & Gurney, 2005). There are several hypotheses for this increased prevalence, including Newschaffer, Falb, and Guerney's speculation that decreased prevalence of mental retardation suggests diagnostic classification shifting. Wazana, Bresnahan, and Kline (2007) suggested that broadening the diagnostic criteria of ASD from the *DSMIII* edition to the *DSMIV* edition may account for the reported rise.

Although the nomenclature and the diagnostic criteria for autism have changed over the years, the greatly increased prevalence of autism spectrum disorders over the past four decades could not be explained (Blaxill, 2004). Prevalence begs the question whether this represents better detection or a genuine increase (Baron-Cohen, 2000). According to Baron-Cohen, a genuine increase is paradoxical: Disabilities that have a genetic basis and which affect social skills negatively should limit mating opportunities, thereby reducing prevalence over time. Increased prevalence, therefore, means that genetic material has been positively selected, indicating that HFA/AS is a difference, not a disability. To further support his position, Baron-Cohen describes an individual in value-free terms: One who is immersed in things rather than

people. However, this drastically increased prevalence of ASD presents a major challenge to the nation's special education service systems (Newschaffer, Falb, & Gurney, 2005).

Current Legislation and Legal Implications

Individuals with Disabilities Education Act (IDEA) as a provision promotes collaboration between schools and parents based on two principles: a) parent participation; and, b) procedural due process (Lake & Billingsley, 2000). The IDEA Amendments of 1997 expanded the role of parents in special education and related services. Under the previous IDEA legislation, parent participation was not required in making decisions regarding their child's eligibility and placement for special education and related services. Parents are now intentionally included as members of the groups making such decisions (National Information Center for Children and Youth with Disabilities [NICHCY], 1998). Given their in-depth experiences and history of their children's development, parents often possess a wealth of knowledge about their children's behavior (Sansosti, Powell-Smith, & Cowan, 2010). Research suggests that parental involvement leads to a) increased student achievement; b) enhanced study skills; c) improved school attendance; and, d) fewer discipline concerns. Sansosti, Powell-Smith and Cowan contend that parental involvement may be the most critical factor for academic and behavioral success of children with HFA and AS.

Educational Placement and Services

Educational placement of students on the autism spectrum appears to be highly related to cognitive ability and communication skills. Students with ASD placed in special education classrooms were more likely to perform at lower ability levels (White, Scahill, Klin, & Volkmar, 2007). Although the majority of individuals with ASD have a milder form of the disorder, research has often focused on the more severe forms (Tsatsanis, Foley, & Donehower, 2004). Consequently, little is known about the educational needs and effective treatment of individuals with ASD in college settings (VanBergeijk, Klin, & Volkmar, 2008).

Prevalence figures and numbers of students served under the IDEA diagnostic category of autism are available; however, these data make no distinction regarding the academic functioning level of students with an ASD. Educational interventions must be tailored to the overall developmental status, specific strengths, and needs of each child identified as having an ASD (CDC, 2006). One of the core provisions of the IDEA is that students with disabilities, including students with an ASD, are entitled to education in maximally normalized settings that offer the greatest opportunity for contact with typical peers (least restrictive environment, LRE) (Simpson, deBoer-Ott, & Smith-Myles, 2003). The academic, social, language, and behavioral challenges present in students with ASD have given rise to various treatments and interventions to facilitate integration of students with ASD in mainstream settings (Simpson, deBoer-Ott, & Smith-Myles, 2003; Wilkinson, 2005). By contrast, White, Scahill, Klin, Koenig, and Volkmar (2007) cite research arguing that regular classrooms may, in some cases, be contrary to the IDEA mandate for appropriate education. The diverse needs of the student with an ASD may be so great that the ability to accommodate the academic and socio-behavioral needs in the general

education setting may not be possible. The ‘one-size-fits-all’ educational placement recommendation for students with ASDs is not possible: Placement decisions must be highly individualized (White, et al.).

Educational Challenges

Students with ASD who have strong language and cognitive skills may be academically successful in specific subject areas; however, severe social impairments frequently compromise success in a regular education classroom (Tsatsanis, Foley, & Donehower, 2004). In terms of their learning characteristics, students with ASDs frequently a) display a wide range of language and communication ability; b) encounter difficulty with unmodified curriculum; c) have an obsessive insistence on environmental similitude; and, d) frequently interrupt the learning environment with atypical and repetitive behaviors (Simpson, de Boer-Ott, & Smith-Myles, 2003). Simpson, de Boer-Ott and Smith-Myles propose a collaborative educational model that includes: a) components of environmental and curricular modifications; b) social support; c) coordinated team commitment; d) recurring evaluation of inclusion procedures; and, e) collaboration between the home and school.

Social and Emotional Challenges

Social isolation and victimization by peers is a frequent problem for children with ASD (Tsatsanis, Foley, & Donehower, 2004). Children with ASD present with more social isolation and loneliness than their unaffected peers; however, children with ASD on the higher end of the

spectrum are more likely to compensate for their social skills deficits with their high cognitive ability (Bauminger, Shulman, & Agam, 2003). Regardless of ability to compensate, qualitative aspects of social behavior of the child with ASD differ from their unaffected peers' social behavior (Bauminger, Shulman, & Agam). The ability to develop friendships is a challenge for children with ASD: friendship requires social skills, and social skills develop through friendships. White, Scahill, Klin, Koenig, and Volkmar (2007) report that even when students with ASD are not isolated from their peers in a mainstream class, this population is not well integrated within their peers' social networks.

Parents play a key role in the formation of friendships; yet, once established such friendships are typically centered on structured activities rather than activities requiring high levels of social engagement (Bauminger & Shulman, 2003). Bauminger and Shulman stated that children with ASD need help in the development and maintenance of peer relationships, and a lack of peer relationships and friendships contributes to adjustment problems later in life. Research by Myles (2005) indicated that children and adolescents with ASD on the higher end of the spectrum have the social maturity of one who is one-third to two-thirds their age. In a reflection of his work with children with ASD, Billington (2006) reported that people and objects in the environment can exacerbate social isolation for children with ASD, and suggested the remedy for this situation may be in our (non-autistic educational practitioners) ability to be sensitive to the needs and feelings of the child with autism.

Addressing the issue of social skills deficits and social skills instructional programs for adolescents with ASD, Webb, Miller, Pierce, Strawser, and Jones (2004) maintained that a successful social skills instructional program could result in noticeably improved skills as rated

by others. Webb et al. indicated that mastery of specific social skills may take place in specific settings; the challenge is to promote generalization of the learned skills in new environments and situations. Welton, Vakil, and Carasea (2004) assert that inclusion plays a vital role in the successful integration of social skills, and a team approach including parents, teachers, and classroom peers is required. The interaction and collaboration of all individuals involved, including the child with ASD, is necessary for skill acquisition and retention.

A plethora of literature exists which presents the social and emotional issues adolescents and their families face during the adolescent developmental period. Commonly noted is an increase in parent-adolescent conflict or disagreement (Steinberg & Morris, 2001). While the source or cause of this increase is debatable, no research was found which indicated that adolescents with ASD are impervious to the increase in conflict. Frea (2010) noted that during adolescence, social, communication, and behavior problems of adolescents with ASD become more pronounced. Not only does a greater prevalence of students with ASD in their adolescent period of development place a greater burden on families, but on the school administrators as well (Frea).

Lived Experiences

Lived Experience: Students with ASD

Richard Exley, an adult with ASD, stated that we can learn about autism from people without autism; however, real experts are those people with autism (Hesmondhalgh & Breakey, 2001).

Michael John Carley, an actor and playwright with autism, commented:

I love the way my brain works, I always have and it's one of the things I can now admit to myself. I like the way I think in terms of numbers. I like the way I visualize things. I like the way most especially that I can bury myself in work that I love to a degree that makes everybody else in the world look at me and go, 'God! I wish I could do that.' No, I am not changing anything (Shapiro, 2006).

While most research is descriptive of the environment in which students with ASD are educated, little is known about the experiences of students with ASD in school settings (Newman, 2007). Humphrey and Lewis (2008) described individuals with ASD as a group *on* which research is conducted, rather than a group *with* whom research is conducted. Humphrey and Lewis' report indicated that researchers make an assumption that students with ASD are academically capable and can cope in mainstream classes. Students with ASD, on the other hand, report that the noisy, chaotic environment and increased exposure to social vulnerability are often overwhelming for them.

Lived Experiences: Parents of Children with ASD

Parents of a seven year-old boy with autism communicated their educational experience with this statement:

We initially felt a sense of relief that responsibility for Tom would now be shared, but this soon turned to disappointment when our intimate observations were not apparently valued, nor incorporated into teaching process at school (Billington, McNally, & McNally, 2000, p. 62).

The parents believed that school emphasized what he could not do, and any lack of progress was the boy's fault. The parents made a strong plea to educators to be aware of the profound impact words and attitudes can have on the relationship with parents: Parents are the best resource for information about the child (Billington, McNally, & McNally). Parsons, Lewis, and Ellins (2009) found a key factor in parental (dis)satisfaction with the educational system related to the extent to which educators understood the nature and condition of the students' difficulties and needs.

Stoner et al. (2005) identified recommendations that were important to parents, but were absent from the parents' lived experiences. Among their recommendations were: a) listening to parents with care and attention; and, b) providing parents with research-based information about ASD and special education services. The ultimate goal for parents and educators is to meet the needs of the child, and when parents and educators have common ground for understanding, then the attainment of the goal is greatly enhanced (Stoner, et al.). When schools and parents of children with ASD, or any disability, have different ideas about the child or his/her needs, then conflict tends to increase until there is resolution to the difference.

Educators must listen to parents' ideas of long- and short-term goals for their children: This improves the necessary partnership between schools and parents in the process of education for children with disabilities (Lake & Billingsley, 2000). Such a partnership is often difficult to establish, however. In their qualitative study, Blue-Banning, Summers, Frankland, Nelson, and Beegle (2004) identified six specific indicators of professional behavior that facilitated a collaborative partnership between schools and families: a) communication; b) commitment; c) equality; d) skills; e) trust; and, f) respect. Operationally defining these terms in the construct of partnership will assist in the development of appropriate practice and teacher preparation. Although recommendations were made about the parents' responsibility in establishing this partnership, the focus of the study was on what professionals needed to do to ensure high-quality partnerships. Establishing a collaborative partnership between families and professionals leads to fewer cases of mediation, due process hearings, and litigation. The over-arching goal of establishing collaborative partnerships with families is greater success for the students with disabilities (Stoner, et al., 2005).

Research documents great levels of stress among parents of children with ASD. Parents were stressed and exhausted when they felt a need to fight the educational system on behalf of their child (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004). Research by Myers, Macintosh and Goin-Kochel (2009) indicated that parents of children with ASD have higher levels of stress than parents of children with other disabilities. When diagnosed later (after the age of eight years), the experiences the child and family went through added to the anger the parents felt toward the educational system (Hesmondhalgh & Breakey, 2001). An additional source of major stress and frustration cited by parents was the result of frequent phone calls

from the school due to their child's behavior problems (Myers, Macintosh, & Goin-Kochel).

Common Themes of Students and Parents

To date, scant research is available that describes common themes and/or educational experiences between students with ASD and their parents. The National Longitudinal Transition Study-2 (NLTS2) presented information obtained via telephone interviews and mail-in surveys comparing responses of students with ASD and his/her parents (Wagner, Newman, Cameto, & Levine, 2005). This survey incorporated a large sample of students with disabilities and their parents. The focus of this survey was on student and family characteristics, nonschool activities, satisfaction with school programs, and activities after high school. (Wagner, Newman, Cameto, & Levine). Comparisons were made between students' responses and parents' responses on the general survey questions on these topics; however, an in-depth, introspective approach to the lived experiences of these research participants was not obtained.

Frey (2010) suggested that the preparation of adolescents with ASD for success in adult life hinged on a team approach: the individual with ASD, family members, professionals, and others who may interact through a meaningful, positive relationship with the individual with ASD. Frey also stated that developing an educational program that will build independence and an optimal quality of life would be very difficult unless the program included a shared vision and a well-thought out plan that included as many people as possible. Listening to the lived experiences of individuals with autism and their parents is one way in a shared vision may be fostered (Billington, McNally, & McNally, 2000).

Phenomenological Research

Literature has shown that phenomenological methodology is a research technique that allows for gathering and documenting the lived experiences of the individuals under study (Fraenkel & Wallen, 2006). Phenomenological research is concerned with understanding experiences from the perspective of the individual in the situation (Lester, 1999). Groenewald (2004) stated the operative word in phenomenological research is ‘describe.’ Groenewald continued to explain that the data obtained, through in-depth observations and interviews, are *explicitated* rather than analyzed. Explicitation attempts to describe the phenomena as a whole, rather than analysis which would break the phenomena into parts and sub-parts.

Expert Focus Group

The use of a focus group is an established method in qualitative research. In general terms, a focus group is a research technique that collects data through group interactions on a topic that is determined by the researcher; the researcher’s interest provides the focus (Morgan, 1997). For the purpose of surveys and questionnaires, an expert focus group is an effective method for reviewing, making recommendations, and identifying problems with a research instrument. The strength of this process is in diverse experiences and expertise of the group (Czaja & Blair, 2005). National Board Certified Teachers (NBCT) in the area of Exceptional Needs Specialist have demonstrated a high level of understanding of the nature and needs of diverse groups of students with disabilities. Each NBCT has demonstrated achievement of rigorous standards through intensive study, expert evaluation, self-assessment, and peer review

(National Board for Professional Teaching Standards, n.d.)

Summary

Prevalence of individuals diagnosed with ASD has risen significantly, challenging educators to provide appropriate educational programs to meet the students with ASD's learning and social needs. Students with ASD report feeling rejected and ignored. They have little input about their educational program. Parents play a crucial role in their child's social development, and now have a greater role in the special education process. Conflict between educators and parents of students with ASD is documented, as is the need to build collaborative partnerships. A shared vision and an educational plan may lead to greater independence and quality of life for the individual with ASD and his/her family. The suitability of phenomenological research methodology, and the use of an expert focus group for interview questions for this study were presented.

CHAPTER 3

METHODOLOGY

Introduction

This chapter describes the methodology of this qualitative research design. The suitability of qualitative research, as opposed to quantitative research design, is reviewed. Chapter 3 includes the following: a) the overarching research questions; b) a description of population characteristics and sampling methods; and c) the procedures that were used to enhance validity and reliability in qualitative research. Methods of and procedures for data collection and data interpretation are presented.

Phenomenological Research

While quantitative research subsumes a medical model aspect of disability, i.e., the child is viewed as permanently and innately flawed, qualitative research views the child's disability in terms of the social construct dependent on the nature of school and societal practices (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). Another source distinguishes quantitative research from qualitative research by explaining that quantitative research answers the questions: "What and How Many?" while qualitative research answers the questions: "How and Why?" (SDS Research, n.d.).

Phenomenological research assumes some commonality to the perception of human beings, and the way in which they interpret similar experiences (Fraenkel & Wallen, 2006). In phenomenological research, neither a treatment group nor manipulation of any variable is part of

the research process. Phenomenological research assumes there are many ways of interpreting the same experience. The critical characteristic of phenomenological research is that the subjective experience is the center of inquiry (Ary, Jacobs, Razavieh, & Sorensen, 2006). This research used a phenomenological approach to gain insight into the lived experiences of graduated students with ASD and their parents in a large urban public school system in the southeastern United States. Lived experience reports provide in-depth data from those who have directly experienced the phenomenon of interest (Patton, 2002).

In the decision to use a qualitative study methodology, the question of subjectivity and validity often arises, as subjectivity is inherent in qualitative studies. In actuality, this subjectivity – explicit personal positions and perspective – is of great value to phenomenological research (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). Establishing credibility and trustworthiness of the data collected is critical in qualitative research. To this end, an expert focus group will participate in the development and finalization of interview questions. To further enhance credibility and trustworthiness, the collection and interpretation of data followed stringent procedures (Czaja & Blair, 2005).

The researcher used Hycner's (1985) archetypal guidelines for phenomenological research as the basis for the data explicitation process. The compilation of data describes the fundamental social/behavioral and academic experiences of subjects participating in this urban public school research study. This qualitative research method, phenomenology, is committed to the description of experiences, rather than explanations or analysis of experiences (Moustakas, 1994). Groenewald (2004) cautions about using the term *data analysis*, preferring instead the

term *explicitation*. Groenewald clarifies that *analysis* means to break into parts, and hence a loss of the whole phenomenon; *explicitation* investigates the phenomenon in the context of the whole.

Archetypal guidelines for conducting phenomenological research as outlined by Hycner (1985) continue to be used by many in current phenomenological research: Calvey and Jansz, (2005); Ewart, 2002; Macfarlane, 2007; Mertzman, 2008; Murphy, 2009; Smaldone, Harris, and Sanyal, 2008; Twiselton, 2007; Uny, 2008; and Wolf, 2008). Hycner's guidelines for phenomenological research are intended to help researchers be true to the subject's experience, and provides a methodological framework for this research design.

Qualitative Research Design Procedures

Research Questions

This qualitative phenomenological study was guided by three research questions:

1. What are the lived experiences of students with ASD who have graduated from a large urban public high school in the southeast United States?
2. What are the lived experiences of the parents of the graduated students with ASD in the large urban public school system?
3. Are there common themes between the graduated students' lived experiences and the parents' lived experiences? If so, what are the commonalities found in the data?

Responses from the subjects' lived experiences provided data in two specific areas of this study: a) academic support experiences and b) social support experiences. Subsidiary questions

were asked of the subjects in order to gain greater understanding of and insight to the subjects' experiences.

Expert Focus Group: Selection and Purpose

Use of an expert focus group to determine interview questions augments the validity of research. While consensus of an expert focus group was neither required nor desired, the ideas expressed by the focus group provided greater breadth and depth to the collection of subsidiary interview questions (Fraenkel & Wallen, 2006). To determine the validity of the study's research questions and subsidiary questions, a focus group of exceptional education specialists were consulted. The expert focus group participants a) recommended revisions and/or validated the study's research questions, and b) finalized the *Guide and Subsidiary Questions* that were asked of the subjects: graduated student and parent.

Five experts in the field of special education, with knowledge of ASD, were selected to participate in the expert focus group. The selected experts, all known by the researcher, hold National Board Certification in the area of Exceptional Needs Specialist. Each expert was contacted by the researcher in person to verify his/her willingness to participate in the expert focus group.

Prior to meeting with the expert focus group members, the researcher generated broad guide questions regarding a) lived academic experiences of graduated students with ASD and their parent(s); b) lived social experiences of the graduated students with ASD; and, c) student/parent involvement in the educational process. From these guide questions, subsidiary

questions were developed. These questions represented current research in ASD, as reviewed by this researcher.

The study's research questions, and potential *Guide and Subsidiary Questions* for each subject group interview (student and parent) were distributed to the expert focus group members for their review and validation. Using the scoring rubric provided, the expert focus group members rated each *Guide Question* and *Subsidiary Question* as *Acceptable*, *Unacceptable*, or *Needs Revision*, based on his/her understanding of current research (see Appendix E). The expert focus group was given one week to submit feedback on the proposed questions. The researcher collected and consolidated the expert focus group members' opinions on the proposed guide questions and subsidiary questions. For a question to be included in the study, at least three of the five expert focus group members must rate the question as *Acceptable*. The final form of the interview questions were revised, as recommended, and used in the interviews with the research participants. (See Appendix C for the list of *Guide and Subsidiary Questions: Student Interview*, and Appendix D for the *Guide and Subsidiary Questions: Parent Interview*.)

Subject Selection: Procedures

Purposive sampling was used to identify the subjects being investigated in this study (Ary, Jacobs, Razavieh, & Sorensen, 2006). In conjunction with officials in the Office of Special Education of this large urban school district, a list was generated of graduated (former) students who have the disability category of autism and who graduated from high school with a standard diploma since June 2005. These students have met the diagnostic criteria for ASD under that Florida Department of Education guidelines (Florida Department of Education, 2007) as

described in the definition of terms. In accordance with the guidelines set by the Family Educational Rights and Privacy Act (FERPA) directory information was provided to the researcher for this identified population of students (Florida Department of Education, 2009).

The list of possible subjects included graduated students throughout the large urban school district. The researcher contacted the parents of the identified students via telephone, and explained the nature of the research. During the phone conversation, the researcher explained that both the student and his/her parents must be eligible and available to participate in order to be included in this study. If more than five students and his/her parent(s) had indicated their willingness to participate and met the qualifications of the study, priority would be given to the most recent graduates, whose recall of specific details and information would yield less opportunity for refabrication (Wolfe, 2001).

Subject Selection: Students

The target student population for this study was students with ASD who graduated with a standard diploma from the specified large urban public school system since June 2005. Four additional caveats were met for a subject to be included in the study. Each student:

- attended school in the large urban school district for at least the past four years of his/her school experience;
- received special education services or accommodations under the label of autism;
- had the label of autism determined by a school psychologist either through psychological testing or by review and acceptance of a private psychologist's report;
- communicated in English, either orally or through word-processing responses.

As students were accepted into the study, they received a designation code, assigned by the researcher, to protect the subject's identity. The first student accepted was designated S1 and his/her parents P1. The second student and parent group was designated S2 and P2, respectively. This coding pattern continued throughout the sample groups (one to five).

Subject Selection: The Parent(s)

The family members who participate in this study were the parent(s) of the student selected for this study. Parent subjects include mother, father, or both mother and father. Parents may be biological parents, stepparents, or adoptive parents.

Parents agreed to participate in order for their son/daughter to be accepted into the study. Parent(s) were interviewed separately from their son/daughter; however, if both parents chose to participate in the interview, the parents were interviewed together.

Parent(s) communicated in English, either orally or through word-processing responses. Parent(s) had a printed copy of the *Guide and Subsidiary Questions: Parent Interview* as the researcher conducted the interview orally.

Validity and Reliability

In qualitative research, validity and reliability apply to the observations researchers make and the responses researchers receive to the interview questions (Fraenkel & Wallen, 2006). Essentially, the validity and reliability of a qualitative study becomes part of the process of the study. Qualitative studies do not yield a fixed number to be compared to others in a testing

manual, as in quantitative studies. Nonetheless, establishing validity and reliability of a qualitative study is essential so that meaningful outcomes are produced which may encourage other researchers to replicate the study at another time.

Validity

Validity determines whether research truly measures what it was intended to measure, and how truthful the research results are (Golafshani, 2003). The validity of qualitative research outcome is largely dependent upon the ability of the researcher to reduce personal bias during the interview and interpretation, as well as the researcher's ability to draw out meaningful information from the subject (Moustakas, 1994). Extensive quotations from the transcripts of interviews, as well as an independent rater to check the researcher's work, helped to establish greater validity for this study (Ratcliff, n.d.). An expert focus group to evaluate the *Guide and Subsidiary Questions: Student/Parent Interview* was also used, and helps augment the validity of this research.

Reliability

Establishing reliability of the data collected is critical in qualitative research. To that end, the development of interview questions and the collection and interpretation of data followed stringent procedures. All interview questions were asked verbatim to each of the subjects, as prepared and exhibited in Appendix B (for students) and Appendix C (for parents). To enhance reliability of findings between the student and parent responses, the wording of *Guide and*

Subsidiary Questions for the students' interviews and for the parents' interviews was comparable, with adjustments for subject/pronoun substitution. Reliability of the research was addressed through listening to the audio-tapes multiple times by the researcher, and verification of a sample of the tapes by an independent rater. A Cohen's Kappa statistical analysis was conducted to determine the inter-rater reliability between the researcher and an independent rater.

Interview Procedures

Once the subjects for the research study were identified the researcher contacted each graduated student and his/her parent(s) by telephone to determine the interview location and time, and to answer any questions the subject may have. Four local public libraries, located in the southern regions of the urban school district, have rooms available for private use. Convenience of the location for the subjects, as well as hours and days of operation of the particular library, were part of the determining factor for the location decision for each set of interviews. Other locations, based on the convenience to the subjects, were considered. Even though graduated students and their parent(s) arrived together at the designated location, the student interview and parent interview were conducted separately, maintaining the confidentiality of their responses.

At the time of meeting the subjects, the researcher spent several minutes talking with both the graduated student and his/her parent to help establish rapport prior to beginning the interview. Following that, the Letter of Introduction (see Appendix F) was reviewed with each of the graduated students and his/her parent(s). Each subject was, once again, reassured of

anonymity throughout the research process. Responses to the interview questions were taped in their entirety.

During the interview, the researcher asked each subject all guide and subsidiary questions verbatim. An explanation of anything the subject did not understand, or definition of an unknown word was permitted. The researcher could also provide examples to clarify the question. The interview session was not given a time limit, and the interviewee could request a break at any time. The interview could be continued on a subsequent day if deemed necessary by either the researcher or the subject(s), although that did not occur in this study.

Data Collection

From the first guide question through the summary of the subjects' responses, the interviews were audio recorded and saved with each subject's code for identification. Each interview was recorded using three different methods: a digital audio recording device, a mini-cassette tape audio recording device, and a Pulse™ SmartPen (Livescribe, n.d.). The SmartPen digitally audio recorded the session while also digitally video-recording what was written on SmartPen dot paper. The data from the SmartPen was downloaded to the computer, and all the written field notes were saved together with the associated audio recording.

During and immediately after each interview, the researcher used the SmartPen and the dot paper to write field notes denoting subject's body posturing and other information about the subject's interview that may not be detected through the audiotape.

A password-protected laptop computer, accessed only by the researcher, was used for the transcriptions. Audio recordings of the interview sessions were transcribed by the researcher to

ensure the accuracy of the responses and to maintain the reliability of the information. The researcher listened and re-listened to the audiotapes to verify transcripts and to identify possible explicitations and themes. Audiotapes and transcribed data were, and will continue to be, maintained in a locked file cabinet by this researcher in order to provide evidence of any questions that result from this research.

Data Explicitation and Theme Identification

The purpose of explicitation is to gain a fundamental understanding of the subjects' lived experiences. The accumulation and explicitation of data will contribute to the body of research examining parents' and students' perspective of academic and social education programming for students with ASD.

Upon completion of the interview process, the researcher began the review of collected data by explicating the subjects' statements using Groenewald's (2004) and Hycner's (1985) guidelines for phenomenological analysis as the underpinning model. Procedural steps follow:

- 1. Interview tapes were transcribed, and field notes which include non-verbal and para-linguistic communication were noted within the transcription. Field notes written using the SmartPen were referred to as the audio tape was transcribed. This facilitated the ability to note units of general meaning.
- 2 . Researcher intentionally set aside presuppositions, with the intention of understanding the subject's point of view.
- 3. Researcher listened to the audiotapes and read the transcripts, looking for a sense of the whole.

- 4. Researcher delineated units of general meaning from the transcribed interview. This part in the process was a general condensation of what the subject had said, but was not concerned, per se, with the research question.
- 5. Researcher delineated units of meaning relevant to the research guide question.
- 6. Researcher determined whether units of meaning with a distinct, common thread could be clustered together.
- 7. Researcher looked for themes among clustered units of meaning.
- 8. Researcher wrote a summary for each individual interview.
- 9. From the data provided by the interviews, a compilation of themes, both general and unique, described the fundamental social and academic experiences of the students and the parents in public school settings (Fraenkel & Wallen).
- 10. A compilation of data suggested general agreement or general disagreement between the subject groups: graduated students and their parents. Responses of each graduated student with ASD and his/her parent(s) were scrutinized together to ascertain whether there was commonality. A three-point scale (agree/disagree/uncertain) was used in these procedural steps (Appendix H).

Any factor in which there was consistent agreement of several subjects could suggest strong inference. These data may be considered for program planning and development for students with higher functioning ASD.

The brief summary of data between the graduated student and his/her parent was examined to determine whether there was general agreement or disagreement in their responses for each question. A copy of the brief summary of data was given to one of the expert focus

group members to perform an independent evaluation on the agreement or disagreement of response. The transcribed responses were also available to verify meaning during this independent evaluation process. Results of the researcher's and the independent evaluator's ratings were compared; a simple ratio of rater agreement as well as a Cohen's Kappa was performed.

Reliability and Validity of Coding

Prior to coding the comparison of responses of the graduated student to his/her parent(s), the researcher met with the independent rater to discuss the protocol for scoring. A clear indication of agreement or disagreement is not always evident in qualitative data; subjectivity is involved in interpreting what is said in the interviews. In this study, the researcher and the independent rater agreed upon a three point scale to compare the students' responses with the parents' responses: agree, disagree, and uncertain. Inter-rater reliability was strengthened by establishing clear guidelines. If the raters have clear, concise instructions about how to rate the comparisons for agreement, the inter-rater reliability increases (Shuttleworth, 2009). Once the response comparisons were rated for agreement, disagreement, or uncertain, the scores were entered into SPSS software to determine inter-rater reliability.

Summary

The methodology to determine the lived experiences of students with ASD and their parents in the academic and social experience of public school education was described in this

chapter. A phenomenological methodology, based on Hycner's guidelines, was used to extract themes from students and from parents. Student themes were compared with parent themes to identify issues that were similar, and issues in which there was departure between the student and his/her parent. Explication of the graduated students' lived experiences, as well as the parents' lived experiences, were described in great detail for the purpose of understanding the perspective of the graduated students with ASD and his/her parents. Great care was given to bracket the researchers' bias or opinions. The insights gleaned from the subjects' lived experiences may provide the basis for program strategies to optimize student success and reduce parental dissatisfaction.

CHAPTER 4

PRESENTATION AND EXPLICITATION OF THE DATA

Introduction

The purpose of this phenomenological study was to gain insight into the lived experiences of graduated students with ASD and their parents while enrolled in an urban public school. Three research questions led to the composition of the three guide interview questions, with five to eight subsidiary questions for each question. This research required the use of an expert focus group to validate the interview questions. After interview questions were validated, the researcher conducted interviews with five graduated students with ASD and his/her parent(s). Individual members of the expert focus group assisted with assessing the accuracy of the interview transcriptions and validating the explicitations created from the interviews. Reliability of the research process was addressed by the parallel construction of the interview questions between student and parent, and by the procedures that were consistently adhered to throughout the interview process.

Following this introduction, Chapter 4 presents a) the results of the expert focus group's evaluation of the interview questions; b) the demographic characteristics of the participants; c) the qualitative data results based upon the interviews; d) the identified themes from the explicitations; and, e) the results from the Cohen's Kappa evaluation of inter-rater agreement. Chapter 4 concludes with a summary of findings through the phenomenological process. The interview data are presented in various formats as appendices:

- Appendix I: Transcriptions of Graduated Student Interviews;
- Appendix J: Transcriptions

- Appendix Q: SPSS Output: Cohen's Kappa Statistics on Inter-Rater Agreement of Parent Interviews;
- Appendix M: Brief Summary and Commonalities of Graduated Student Responses;
- Appendix N: Brief Summary and Commonalities of Parent Responses;
- Appendix O: Comparison of Individual Graduated Student Responses to Parent Responses.
- Appendix P: Comparison of Graduated Student Commonalities to Parent Commonalities

Qualitative Research Process

Interview Questions

The researcher compiled three guide questions with subsidiary questions (five to eight) for each guide question. These guide and subsidiary questions supported the three research questions, and reflected current research in ASD. Sets of interview questions were drafted for the graduated students, and a set for the parents. The student interview and parent interview questions paralleled each other for ease of comparison and explication.

Once the interview questions were drafted, the researcher contacted five National Board Certified Teachers in the area of Exceptional Needs Specialist. All five agreed to participate in the expert focus group, which validated the interview questions for this research. The criterion required for a question to be included in the interview stated that three of the five expert focus group members must rate the question *acceptable* based on the rubric provided. Four of the five experts rated all the questions *acceptable*, which exceeded the required three out of five responses for inclusion in the study. The fifth expert indicated 25 of the 40 subsidiary questions

were *unacceptable*, with associated comments such as the question was “too open-ended” (four comments) , “too qualitative” (three comments), and “touchy-feely question” and “too subjective” (one comment each). The established criterion of at least three of the five expert focus group members rating each question as *acceptable* was met for all guide and subsidiary questions, and were used in the interviews of both the graduated students and his/her parent(s). Appendix F provides the summative feedback of the expert focus group’s comments and ratings on the interview questions.

Research Data

Subject Selection

Upon approval of this research study by the University of Central Florida’s Institutional Review Board, and this urban school district’s research review board, the researcher contacted, by e-mail, the district supervisor for students with ASD requesting information on potential subjects for this research. The district supervisor forwarded the researcher’s request to the president of a local autism society chapter, as well as to autism support staff who work throughout the district. The requests yielded a total of six names of potential subjects. Upon attempting to contact the potential subjects it was evident that one of the potential subjects had moved out of town, and no forwarding information was available through the school district. All of the remaining potential subjects agreed to participate in the study.

Of the five graduated student participants, four were male, one was female. All had graduated from high school with a standard diploma, and all were attending college at the time of

the interview. Four of the five graduated students resided with both mother and father; one student, S1, lived with his divorced mother. All students graduated from high school in the year 2006 or later, and all students were 19 years of age or older. Three of the students were of Hispanic descent, one was of Asian descent, and one was Caucasian. All five mothers participated in the interview process, and two fathers accompanied and participated with the student's mother. All students were biological children of the parents. Table 1 provides descriptive information of the graduated students who participated.

Table 1: Graduated Student Attributes

				Year	Attending	
	Gender	Age	Ethnicity	Graduated	College?	Parent Participating
S1	Male	20 yrs.	Hispanic	2009	Yes	Mother
S2	Male	22 yrs.	Hispanic	2007	Yes	Mother and Father
S3	Male	22 yrs.	Asian	2007	Yes	Mother
S4	Male	19 yrs.	Hispanic	2010	Yes	Mother and Father
S5	Female	23 yrs.	Caucasian	2006	Yes	Mother

Interview Procedures

As names of potential research participants were provided by district ASD support personnel, the researcher immediately attempted contact with the families. The initial contact with participants was always made by telephone, and in each case the mother of the graduated student was the respondent. The researcher read the Letter of Introduction (Appendix G) and answered any questions asked by the participant. In each of the five cases, the mother agreed to

participate, but indicated that she would have to check with her son/daughter. If a parent didn't reply within two days, the researcher placed a follow-up phone call. All graduated students agreed to participate.

At the time the parent gave final approval to participate, a meeting time and location was arranged. Three of the interviews were conducted in private rooms at public facilities (the library and school sites), and two of the interviews were conducted in the families' homes at the parents' requests. The researcher spent several minutes with the graduated student and his/her parent(s), to establish rapport. The researcher reviewed the purpose of the research, and presented the student and parent(s) the Consent for Participation papers to sign. The graduated students/parents were informed that in all transcriptions of the audio recorded data, they would be identified only by their assigned code (e.g. S1, P1; S2, P2; and so on).

To lessen any anxiety, the graduated student was consistently interviewed first. Parents were not present during their child's interview, and were not able to hear their responses. Conversely, when the parent(s) were interviewed, the students were not present and did not hear their parent's responses. All interviews were completed in one session, with each interview lasting from 35 minutes to approximately one hour. Following the interviews, the researcher brought closure through conversation with the graduated students and his/her parent(s); two of the parents requested a copy of the research once it is completed.

Explicitation of Data

Upon completion of the interview process, the researcher reviewed the collected data by explicating the subjects' statements. The researcher explicitated the data using the following protocol:

1. The audio taped interviews were transcribed on a password-protected laptop computer.
2. Responding specifically to each of the three general guide questions, the interviews were summarized.
3. Field notes and observations were included in each summary.
4. Four transcribed interviews were randomly selected and one of the expert focus group members listened to the audio recording of the interviews and validated each of the selected interview transcriptions.
5. An Excel spreadsheet was created to record a brief summary of responses for each subject interview.

This spreadsheet of data summaries facilitated the comparison of responses for a) the graduated students; b) the parents; and c) the student to his/her parent(s) (see Appendix M, Appendix N, and Appendix O, respectively). An expert focus group member also reviewed the interview summary spreadsheets, and transcription summary appendices to validate the researcher's suppositions.

Qualitative Research Study Questions and Outcomes

This qualitative study presented three research questions and utilized two subject groups from which to elicit recorded responses: a) the graduated students with ASD, and b) the parent(s) of the graduated students with ASD. For each research question, three guide questions with twenty subsidiary questions formed the framework for the interview session with each subject and subject group.

Review of the responses for guide and subsidiary questions from each subject group revealed commonalities (Appendix M and Appendix N). Supporting data for the identified commonalities are provided. Subsequent to examination of the commonalities, the researcher identified themes which resonated among the responses from each subject group. Following the presentation of the identified themes for each subject group, outliers of responses from each subject group, along with supporting data, are presented. The three qualitative research questions of this study are presented in sequential order. At the conclusion of each research study question, the suggested commonalities and identified themes are stated.

In the ensuing sections where supporting data are given for identified commonalities, *R* indicates prompts or queries made by the researcher; *S* denotes the student's response, with the number following *S* specifying the assigned code of the student.

*Research Question One: What are the lived experiences of graduated students with ASD
in the urban public school system?*

Field Notes of Student Interviews

This section provides a description of the interview setting and characteristics of the graduated student as he/she was being interviewed. The notes are the observations of the researcher, taken during the audio-taped interview.

Student 1 (S1) was at the interview location with his mother when the researcher arrived. The interview location was the private preschool where S1's mother works. S1's affect was flat, he seemed somewhat sullen. He wore a "hoodie" style sweatshirt, and as the interview progressed, S1 put the hood over his head, which fell lower and lower on his face, covering his eyes. S1 made limited eye contact with the researcher. There were lengthy pauses before S1 responded to the questions; he spoke slowly and carefully. S1's responses to most questions were brief, with little elaboration provided. On occasion, the researcher had to probe to get a complete response to the question. S1 let out a sigh, presumably of relief, when he was told the interview was over, and he quickly got up from the table and left the room.

Student 2 (S2)'s interview was conducted in the home of S2 and his parents. S2 was cleanly and comfortably dressed in baggy pants and t-shirt, but wore no shoes. He appeared not to have shaven for a period of days. S2 was friendly and cordial with the researcher. S2 made eye contact with the researcher; however his gaze was prolonged at many times during the interview, making such eye contact uncomfortable. Many times during the interview S2 would snort, but it was not determined whether this was a nervous twitch, part of a sensory discomfort

of too much mucous, or if it was part of S2's ritualistic or idiosyncratic characteristics. The researcher chose not to question S2 about the snorting, in case it was a topic of embarrassment or discomfort. S2 answered the questions with apparent ease, and his affect matched the responses to the interview. S2 smiled as he recalled an enjoyable experience, and he seemed upset when recalling how he was "falsed" when he did not learn a computer application in one of his high school classes.

S3 arrived with his mother at the interview location, his former high school. The interview took place in the late afternoon in one of the high school classrooms. S3 appeared comfortable in the interview environment, and had no difficulty making eye contact with the interviewer. S3's greeting to the researcher was formal in tone. Throughout the interview S3 was polite, and he spoke respectfully of his teachers and his parents. S3's speech lacked fluidity, as he repeated words and phrases. S3 endeavored to be precise in his responses, while also using some-what dated verbiage such as "shenanigans" and "tom-foolery."

S4's interview was conducted in a gazebo outside a public library near the home of S4 and his parents. S4 arrived with his mother and father; later his sister came to the interview, as well. S4 was very neatly attired. He wore eyeglasses that were photosensitive, and which darkened in the outdoor interview location. S4 responded with ease to all the questions, and was calm throughout the interview. S4's speech was slightly pedantic, and at times the researcher had to get clarification of his responses. S4's affect was appropriate to the comments he was making.

S5 was the only female of the graduated student subjects. The interview was conducted at the home of S5 and her parents, in a room that S5's mother uses for her tutoring business.

Rapport was quickly and easily established as the researcher and S5 were wearing identical sweaters. S5 and the researcher also have similar eye color and hair color. As preliminary conversations with S5 and her mother were conducted, many other similarities between S5 and the researcher became apparent, including their pets and the names of the pets. S5 was expressive in her responses, and made good eye contact with the researcher. When the questioning turned to S5's social experiences, she became noticeably distressed, and asked the researcher not to judge her based upon her responses

Identified Commonality #1

Regarding their academic experience in public high school, the graduated students indicated they encountered learning challenges due to having an ASD. This comment was made by four of the graduated students; however, each student presented a unique challenge to his/her learning due to ASD.

Pertaining to guide question #1, which asked the graduated students about their educational experience as a student with an ASD in an urban public school, the researcher asked whether having an ASD affected the student's ability to learn. S1 recalled that he had difficulty with his attention span:

S1: "I think definitely a post-problem for attention span when things weren't very interesting, or when things were too easy or too hard for my skill level."

S2 had learning challenges because he did not understand the details of completing the assignment:

S2: “When they’re trying to explain a project and it has to be done a certain way, I tend to not understand the details—a lot more details. Half the time I would do it in a way that’s, like I’m wrong, I assumed what it’s supposed to be, but now I’m missing this one little detail.”

S3 commented that social situation of learning groups affected his ability to learn in some of his classes:

S3: “As far as education goes, it’s meant to involve everybody. All teachers, just getting the teachers and students together. There are times when students will need to participate in projects together, and they will need to know how to deal with other students.”

R: “The social aspect affects the ability to learn?”

S3: “At least for me it does. I don’t know if that experience applies to other students with high functioning autism.”

S3 commented on students with ASD’s ability to learn:

S3: “The lesson that I’ve learned is that we can’t always have what we want. We have to adapt to our situation because the world won’t always bend over backwards for individuals that have special needs. They have to be able to adapt to their situations. And, it was challenging at first, but eventually it became intuitive, and eventually became a learned pattern of behavior.”

S5 lacked specific skills due to ASD:

S5: “...I had trouble with abstract thinking, and I had trouble with art because of my fine-motor problems and handwriting. I mean, other kids used to make fun of me because I couldn’t draw. I was also not very good at sports; I was very uncoordinated.”

Four of the five graduated students mentioned that having extended time to complete projects and tests was a helpful learning accommodation; two graduated students indicated that preferential seating was helpful, as well.

S1: “Probably extended time [*helpful learning accommodation*], so I wouldn’t be expected to keep pace with non-autistic students.”

S2: “Extended time helped for the tests. Because I can not complete a test on a time limit.”

S3: “Extended time was definitely very useful. It helped me to focus and concentrate more on what I needed to accomplish. And not being around other students also helped me to be in my own zone so that I can get what I needed to do done.”

S5: “Well, I got extended time for tests and assignments.”

Only S4 indicated that there was no learning challenge due to having ASD; in fact, S4 believed that he was able to pay better attention because of having ASD. Also, S4 preferred sitting in the front of the class, although it was never specifically requested. Moreover, S4 indicated it was not the class environment as much as the subject matter that presented learning difficulty.

S4: “Really it’s not the classroom that was challenging; it’s really what I was learning that was challenging.”

R: (*prompted elaboration*)

S4: “Well, to me I believe it was math. That’s the most challenging thing for me. But I can still understand math.”

Commonalities among the graduated students suggested a theme of *learning challenges* due to having an ASD. Table 2 provides brief summaries of students' responses which support this theme.

Table 2: Graduated Students’ Responses Supporting Learning Challenges Due to Having ASD

S1	S2	S3	S4	S5
Needed help understanding the “book stuff.”	Could not understand details to complete projects.	Academic experiences requiring social participation were difficult.	Would lose his train of thought in loud classes.	Difficulty with abstract thinking,, fine motor and gross-motor tasks.
Needed extended time.	Needed extended time.	Needed extended time, preferential seating.	Needed preferential seating.	Needed extended time.
Classes where forced to socialize were challenging.	Project-based classes were difficult.	Negative experiences in physical education.		Needed teachers who were structured, gave clear explanations.
	Needed a patient teacher to keep explaining things.			Needed teachers to present information visually.

Identified Commonality #2

Another recurring response to the subsidiary questions was that the graduated students had difficulty socializing with peers and establishing friendships. Five out of five graduated students expressed difficulty with making friends on a scale ranging from difficult (S5) to very difficult (S1), to impossible (S2). These challenges were evident throughout the graduated students’ interview responses.

S1: “...knew in theory how to make friends, but in practice it was very intimidating.”

S2 indicated that his grade level impacted his ability to make friends.

S2: “ In elementary school it was pretty much impossible. But high school, I made a couple of friends that I’m still in touch with today.”

S2 continues on the topic of his social experience by stating,

S2: “I didn’t talk too much. Other than to the art magnet kids.”

S3 indicated that he was around a lot of Honors and Advanced Placement (AP) students. He had had friends who were smart and ambitious; however, S3 felt detached from these friends:

S3: “I did have friends with people that were smart. They were kind of like nerds, and I was kind of like a nerd. And I felt like these were kind of like the right people to have friends with because they were ambitious, they were hard workers... It was still a degree of detachment from them, just because they were, it seemed, like they were on a kind of level I can’t reach.”

And later, after moving on to other questions in the interview, S3 commented

S3: “In retrospect I still feel like it [social experience] was a bit lacking, because there’s that degree of detachment- like I wasn’t really one of them. Like I felt like I was still in a world of my own, pretty much.”

Rather than being with the students in his Honors and AP level classes, S3 spent time with the social “misfits” of the school.

S3: “They were also- like the misfits and unpopular kids. I wouldn’t say they were bad- they weren’t bad kids... they were like underachievers. I would usually sit with them during lunchtime instead of the smart kids, just because they welcomed me... They liked to have fun and fool around, engaging in shenanigans and tomfoolery. Just because it’s such a laid-back environment I didn’t have to feel so uptight around them.”

Like S3, S5 participated in social activities in school, yet felt a sense of detachment from others in the clubs.

S5: "...like I said, I wasn't really actively in them [social club] I was kind of just—I don't know, just a part...It turns out I almost didn't want to go to Prom because I thought it was too much [social stimulation]. But I kind of went anyway, but like I said, even there I was kind of in the background."

S5 stated that it was difficult for her to make friends, and she was basically a loner. She also stated that she never had a boyfriend.

For the first two years of high school, S4 said he didn't have any friends. In his junior year of high school he decided to "step forth and try to make friends." There were different clubs and activities in which he participated in order to make friends. S4 further stated:

S4: "... I guess I did well for a person with this disorder, but I think I could have done better. [How?] I don't know, maybe... I mean I had friends but I never really had a best friend."

Of the friendships that the graduated students did establish, three students indicated that their friends did not have ASD, while the other two students were unsure. Four of the students indicated that no assistance was provided by school personnel for their participation in social activities at school. When asked to recall a social experience in school, three of the students recalled a negative experience, and one student couldn't recall a social experience at all.

S1: "To put it bluntly, mostly negative [social experiences]. The number of humiliations, embarrassments, and misunderstandings vastly outweighed the positive experiences... I was sitting around with a group at lunch. I had taken a habit of sitting with them every once in a while, but rarely did I speak. This caused one of the group to think there was

something seriously wrong with me. At one point she seemed convinced that I would be, or had been, a serial killer. Not knowing how to express my response, I kind of smiled weakly. I imagine this didn't exactly help her perception, but I wish she didn't have to make that perception in the first place."

S3: "...psychologists tend to say that individuals vividly recall the negative or bad experiences the most, just because they're traumatic. And, if I had to describe a traumatic experience, it would have been P.E. just because I was never very athletic. I was usually picked last, picked-on by other students in that P.E. class. And even just by some random people that I don't even know. Like they act like a bunch of immature assholes, and I don't even know why."

S5: "Like I said, I didn't have too many social experiences. I know that's sad...I mean, there were kids that teased me, if that counts. I can never think of any reason why they would tease me 'cause I never dressed any differently."

These commonalities among the graduated students' suggested a theme that the students had challenges making friends. Table 3 provides a brief summary of graduated students' statements which support this finding.

Table 3: Graduated Students' Responses Supporting Challenges Making Friends

S1	S2	S3	S4	S5
Very difficult making friends.	Making friends in elementary school was impossible.	Didn't know how to hang around with others.	Had no friends for the first two years of high school.	Difficulty making friends; was a loner.
Knew how to make friends in theory; the practice was intimidating.	Made a few friends in high school, but only with those who have similar interests.	Felt detached from peers in classes and school clubs.	Had a friend in elementary school, but couldn't recall a social experience.	Concerned about being judged negatively by others.
Social experiences were humiliating and embarrassing.	Didn't talk much to others, except those with similar interest in art.	Meaningful relationships were developed mostly with teachers.	Never really had a best friend.	Never had a boyfriend.
Didn't want to be social, wanted to be alone.				Was teased by other girls.
				Not an active participant in school clubs and activities.

Identified Commonality #3

Involvement in their educational process was expressed by all of the graduated students, and is the third identified commonality. All of the graduated students participated in their IEP meetings and transition meetings, and all graduated students indicated that their parents participated, as well. Two of the five graduated students specifically stated that they felt comfortable participating in these meetings.

S3: “They [IEP meetings] were very useful for me. I felt comfortable. These were people I was pretty close to. And, they helped me plan out my future.”

S4: “I know about the meetings. Yeah, I went to most of them... They were all right, I mean I was as good as I can be. I felt comfortable, basically.”

Four of the five graduated students believed their parents wished for them to be more socially involved in school.

S1: “I’m pretty sure they would have liked for me to be more social, but at the time I was undiagnosed. They didn’t understand how hard it was for me, and as neurotypicals, they never fully can.”

S2: “They didn’t make me [be involved in social activities] but they did ask if I should go, and stuff. No I- like I said, I don’t do proms or any of that group stuff.”

S3: “They wanted me to have a lot of friends, even though I felt I didn’t really need a lot of friends. At the time I felt that school was really mostly to learn. I think that the primary function of school is still mostly to learn, but I’m now aware that school does offer a much more broad experience for students to enjoy and immerse themselves.”

S5: “...I do have the feeling they sometimes expected more of me socially. Like they would get frustrated that I didn’t have any friends. At my perception of it... I think they would sometimes get concerned with me if I sat by myself at lunch sometimes. But- and I wanted to tell them it wasn’t a big deal, but I was worried what they were going to think.”

Commonalities among the graduated students’ responses indicated that all were involved in their educational process, and all were supported in their educational process by their parent(s)’ participation, as well. Involvement in their educational process is a theme suggested

by the graduated students' responses. Table 4 provides a brief summary of graduated students' responses which support this theme.

Table 4: Graduate Students' Responses Supporting Involvement in Their Educational Process

S1	S2	S3	S4	S5
Participated in all IEP and Transition meetings in high school.	Participated in all IEP and Transition meetings; did not like the experience.	Participated in all IEP and Transition meetings; found the meetings useful.	Participated in IEP and Transition meetings in high school.	Participated in 504 Plan meetings; had a voice in her accommodations.
Attended high school graduation.	Attended high school graduation.	Didn't want to have extended time, but did finally agree with accommodation.	Advocated on his own behalf not to have extended time.	No Transition meeting due to 504 plan.
High school did not adequately prepare for college; experiences were too different.		Recognized a need for a broader experience in high school than only academic accomplishments.	Believed high school prepared him well for college experience.	Attempted classes and activities suggested by parents and teachers.
Did not request anything different from parent.		Continues to meet with Vocational Rehabilitation Counselor.		

Research Question One: Outliers of Graduated Student Responses

While each set of questions had several areas of commonalities in the graduated students' responses, there were some responses that were noteworthy and set apart from the others. S2 had

a unique perspective on the IEP meeting process, indicating that it had been a negative experience, and wished he didn't have to have meetings at all.

S2: "Yeah, I don't like it [IEP meetings] but I did participate. It feels like an innovation."

R: "Intervention?"

S2: "Yeah, is that what you call it? Having all my teachers in one room at once and talking at me. It feels like, oh God, I don't—am I this dumb that they have to work together to get me to pass? It just feels so awkward... I have never been the guy that likes being the center of attention... I would rather not have a meeting, just go about my merry ways... I'll admit some of the things helped, but I didn't like the process of getting it. It feels like when you're in school and you've done something horrible... and you're in the principal's office and they bring the parents in. It felt exactly like that. And you're a little kid and you're just there with your head lowered down, and like I can't believe this. It felt exactly like that. They say this is to help you; why does it make me feel horrible then?"

Another outlier was the intensity with which S1 felt challenged in school due to his social anxieties. S1 described his challenging classes or learning environments.

S1: "That would probably be the ones where I was forced to socialize against my will. Places like P.E., among others, were nothing more than a public embarrassment."

When asked to recall a vivid academic experience, S1 replied after a very long pause:

S1: "I think if I do have any memories to apply, which I'm sure I do, they are probably repressed."

Throughout the line of questions on his social experiences in school, S1's hood on his sweatshirt was inching lower and lower over his face and eyes. When asked if there was anything else to say about his school social experience, S1 responded:

S1: "That it was hellish, and I never want to go through that again."

S1 explained the difficulties with social experiences.

S1: "They didn't understand how hard it was for me, and as neurotypicals, they never fully can."

S1 provided an insight into why others couldn't understand the difficulties he had experienced in social situations:

S1: "At times I felt they were over-estimating me. I think people see my intelligence and think of it as something that makes things easier for me than they really are."

S4's responses were mostly dissimilar from the other graduated students' responses. He was the only student who specifically stated did not want others to know he had an ASD.

S4: "I never told anybody about my – um – I don't know, I just didn't want to tell them about it."

S4 spoke in consistently positive terms regarding the school experience, including social activities. He shared his approach to having a positive experience:

S4: "Well, I tried not to get into any trouble. I focused on my education and make sure my friends were not shady."

The only social experience S4 could recall, however, was that his best friend in elementary school moved to another region. S4 also expressed in literal terms that participation in graduation was necessary to be graduated.

S4: “And for the school activities, I participated in all three of these Senior events. Especially graduation.”

R: “Why ‘especially graduation’?”

S4: Yes, because if I didn’t participate in graduation, I wouldn’t be here right now.”

The intended messages of these outlier responses are important to the individual student with ASD. While having no commonality with the responses of other graduated students with ASD in this research, highlighting the outliers emphasizes the unique concerns which may be necessary for the individual’s academic and social success.

Research Question One: Summary of Identified Commonalities and Themes

Commonalities among the graduated students suggested that a) the academic learning environment was, overall, challenging; b) establishing friends and participating in social experiences was difficult; and, c) participation and involvement in their educational process was evident. From these commonalities, the following themes emerged: a) Learning Challenges; b) Challenges with Making Friends; and, c) Involvement in Their Educational Process.

Research Question Two: What are the lived experiences of the parents of graduated students with ASD in the urban public school system?

Field Notes of Parent Interviews

This section provides a description of the interview setting and essential characteristics of the parent(s). The notes are the observations of the researcher, taken during the pre-interview rapport session and the audio-taped interview.

P1 is the biological mother of S1 and his younger sister. She is divorced from S1's biological father and has been raising the children on her own with infrequent visits by the father. Rapport was easily established as P1 and the researcher had mutual acquaintances. The interview was conducted in a classroom at the private preschool where P1 works. P1 was pleasant mannered and articulate. She answered all interview questions without hesitation. P1 voiced great concern for S1's constant challenges, especially in his socialization. One gathers a sense that P1 is overwhelmed with S1's difficulties, and her lack of ability to make things easier for him. After the interview, P1 expressed appreciation for allowing her to be part of the study, hoping more assistance will be available for students like her son.

P2 consisted of S2's biological mother and father. The interview was conducted in P2's home. The home was neat and cleanly decorated. The parents sat next to each other, across the dining table from the researcher. The parents were very cordial with the researcher, and with each other, as well. Rapport was easily established, and the parents answered all questions without hesitation. Both parents participated throughout their interview, however, the father was more vocal. In many cases, the mother agreed with the father's statement, and then added observations of her own that supported the father's account.

P3 came to the interview with her son at the high school where S3 graduated. The interview was conducted late in the afternoon in a vacant classroom at the school. A petite, middle-aged woman of Asian descent, P3 was very polite throughout the interview process. P3 is the biological mother of S3, and there are two older siblings who reside with S3 and his biological mother and father. Eye contact with the researcher was observed to be somewhat limited, but could be due to cultural factors. English is not P3's first language, and at times, P3 had difficulty finding the correct words to convey her thoughts.

The interview with P4 was conducted in an outdoor gazebo at a library near their home. The mother and father, both biological parents of S4, participated in the interview. The father did most of the speaking during the interview period, but the mother added her own observations at the end of the interview, which complemented and augmented the father's recount. During the parents' interview, their daughter, who is two years younger than S4, also made comments supporting her parents' remarks. This family presented as a warm, caring, and cohesive family unit.

P5's interview was conducted in her home, in a large room that P5 uses for her private tutoring business. P5 is the biological mother of S5, and is married to S5's biological father. P5 has two older children, S5's siblings, who do not reside in the house. The researcher spent approximately half an hour talking with P5 and S5 before commencing the actual interview. P5 had a small, hand-raised parrot in her shirt pocket, and was playing with the bird while she conversed with the researcher prior to S5's interview. There was another bird and also two dogs also present in the house. P5's husband was leaving to do some grocery shopping, and was not present for the interview other than to be introduced to the researcher. During the interview, P5

spoke openly about her experiences in school. It was evident that P5 was highly involved in all aspects of her daughter's education, and advocated strongly for S5 to be in mainstream settings for all classes. P5 voiced being distressed about the negative social experiences her daughter had to endure, and also spoke proudly of S5's academic accomplishments.

Identified Commonality #1

Dialogue with the parents of the graduated students began similarly to the graduated students. Questions such as, Did having an ASD affect your child's ability to learn?, and Did your child participate in a social skills class? elicited responses from the parents which were explicated by the researcher in the same manner as the graduated students' responses.

Four of the five parents responded that having an ASD affected their child's ability to learn. Unlike the students, who each mentioned different reasons for having learning challenges, the four parents indicated that difficulty in social situations hampered their child's ability to learn. Parents specifically mentioned that (dis)comfort in the learning environment affected their child's ability to learn.

P1: "I believe it [having an ASD] affected his ability to learn because having problems with socialization and making friends and expressing his feelings appropriately would make him get more upset and shut down when something did happen. And that affected his learning because he may not have wanted to go to school the next day or participate in the next class 'cause he was too emotionally anxious."

P2: "Basically they have no social life whatsoever because they are not understood, or they do not understand the other children. They have a problem with body language and

recognition. So, all of this affects their interaction with other students where he or she may learn, not only behavior, but learn other things about even the curriculum from the other students—because of a lack of communication.”

P3: “It affects his ability to learn socially. That was his number one problem, socialization... I think what I can remember is the group projects. He thinks that he can do better doing the projects on his own- as far as I can remember- and that he doesn’t trust other students because he would always say that they were laid-back, and he doesn’t join groups. He always ends up doing it on his own.”

P5: “The social challenges, particularly starting in around middle school, affected her learning because of just being in school, being worried about other kids and not feeling comfortable in her classrooms...She finds on-line learning a lot less distracting. She doesn’t have to worry about a lot of things that she would in a classroom situation.”

Four of the parents indicated it was necessary to provide structure and guidance for learning assignments.

P1: “If he asked for help, I would help. But it was more—I would say—guidance in terms of if he asked me ‘What do you think sounds better, this or that?’ or if he was stuck on getting started with something because he’s a perfectionist. So, he thinks about things so much and tries to plan them out so much that sometimes he doesn’t get going.”

P2: “My wife did amazing things trying to organize him. With books, and the binders, and the labels, and the colors...It wasn’t his ability to learn that was the problem; it was the lack of organization. And, it’s still a challenge nowadays. Even more so nowadays when he’s in college and he’s all by himself. Organization is the main challenge.”

P3: “He usually does his own homework. I am just there to support him and just to make sure that he manages his time doing his homework, and make sure that he’s on time doing his homework... I want to make sure that he flips his daily journals and what’s going to be done today and tomorrow.”

P4 indicated that having an ASD did not affect their child’s ability to learn; however, P4 did support S4’s learning by providing structure:

P4: “Well, one thing is that my wife is there all the time, helping him, getting after him, trying to sit with him if he needed it. So, that’s basically—she was on top of that.”

Regarding teacher characteristics which were effective with their child as a learner, three parents said a loving or caring teacher was helpful, and two parents indicated a sense of humor helped. Once again, the idea of (dis)comfort in the learning environment was evident, especially in P3’s response about her son’s ability to relax in certain classes.

P1: “He needed someone that was structured, but yet loving and accepting. You know—someone that would accept him for him, but at the same time would kind of guide him.”

P4: “The fact that they loved him and guided him and they always protected him. Yes, there was an advisor who helped him a lot, she loved him and protected him with everything.”

P5: “Caring. Someone who she knew understood her, who realized that she was very bright. Even though at times there were things she didn’t know that should be obvious.”

P2: “Yeah, this one, like the sense of humor, the teacher that makes the class fun. I think in general most kids relate to that better.”

P3: “He has mentioned a specific teacher who has a really good sense of humor, and when he is in that class that he really learns to relax because the teacher is like very—it’s more relaxing to him than really some teachers are trying to—instead of rigid.”

Commonalities of parents’ responses suggested a theme of learning challenges due to having an ASD in the urban public school setting. A sub-theme of (dis)comfort in the learning environment affecting the students’ learning was suggested in the parents’ responses. Table 5 provides a brief summary of the parents’ responses which support this identified theme.

Table 5: Parents' Responses Supporting Learning Challenges Due to Having ASD

P1	P2	P3	P4	P5
Social aspect of school created anxiety and son would not want to go to school.	Poor organization, social, and communication skills impacted son's school learning.	Son had difficulty learning because of social aspect of school.	Transitions from one school level to another was difficult for son	Sensory distractions and social challenges impacted daughter's ability to learn.
Son needed caring, accepting teachers.	Son needed smaller classes and teachers who were aware of ASD.	Son needed quiet class environments and preferential seating.	Son needed structural support for learning.	Hand-selected teachers in mainstream settings was necessary for success.
Classes requiring verbal participation were difficult for son.	Auditorium style classes were difficult for son.	Son didn't do well with group projects; couldn't trust others in group.	Caring, compassionate teachers were helpful to son.	Noisy classrooms group projects were especially difficult for daughter.
Teachers who used sarcasm or who were inconsistent with discipline were problematic to son.	Son needed teachers who had sense of humor, were organized, fun, and smart.	Teachers with sense of humor helped her son relax in class.		Caring teachers who were good communicators were most effective with daughter.
Use of a laptop would have been helpful for son's success in school.		Son needed extended time, but preferred not to use it; he didn't want to be different from peers.		Extended time, preferential seating, and a pass to see an ASD teacher were necessary accommodations for daughter.

Identified Commonality #2

Five of the five parents indicated that making friends was difficult, to varying degrees, and that there was no social skills class available in the public school that would assist in that process.

P1: “It was always very difficult, and he made friends like within the classroom that he participated in. But it was usually more like maybe one person in each class. But since he didn’t seek them out after classes ended, then they weren’t really relationships that were maintained.”

P2: “It was difficult. Extremely difficult... School social experience was non-existent.”

P3: “It was difficult especially in the beginning of school [9th and 10th grade].”

P4: “Very difficult. Very, very, very difficult. I think he has as friends more girls than boys. The girls love him. But he doesn’t know them. He doesn’t even keep records – I mean telephones, whatever... The girls are more nicer to him, the guys would usually pick on him... He won’t continue conversations, he’s not that social.”

P5: “Difficult. Elementary school I think she was oblivious to it. She was very happy. Everything was fine until middle school. Middle school is challenging for a lot of kids, but she was wronged... You don’t have to have a disability, or in this case a hidden disability, to be ostracized by your peers in middle school. Add to that the naïveté... It took her a long time to differentiate between who’s a friend and who’s a— just an acquaintance. And, who is trying to set you up and deceive you and all that.”

Regarding assistance from school personnel to facilitate their child's participation in school related social activities, three of the parents indicated that no such assistance was provided.

R: "What help did school personnel provide, if any, for your child's participation in social activities?"

P1: "Other than a teacher helping him with being able to go to graduation and facilitating things for him, I can't really recall anything else."

P2: "None. Not that I can recall."

P3: "No, not really. He just found out that they're asking for students to participate, and I said go ahead. Any social activities in school you have to go."

P4 and P5 mentioned having a specific person at school who encouraged their child's participation in activities and assisted with social difficulties.

P4: "Probably the Agri-Science teacher- I think she helped quite a bit... She was always trying to get S4 involved in these kind of activities. She was encouraging. She was a good, good person.

P5: "In the school system it was very good to have a 'go to' person. Not just for her, but for me as well, that understood Asperger's. And so in our case it was Mr. Q. If there was an issue going on, whether it be academic, social, anything that I got wind of, I could e-mail him or call him and he was always very open...He usually went on some of these things [school social activities] because he might have a student or two that was going."

Based on these common responses from the parents, a theme of difficulty making friends is suggested. Table 6 provides a brief summary of responses from the parents which support that theme.

Table 6: Parents' Responses Supporting Difficulty Making Friends

P1	P2	P3	P4	P5
Son had very difficult time making friends in school; did not maintain acquaintances outside of school.	Extremely difficult time for son to make any friends.	Son had a difficult time making friends, especially in the 9 th and 10 th grade.	Son had a very, very difficult time making friends.	Daughter had difficult time making friends since middle school; was ostracized by other girls.
Social situations scared son.	Son didn't want to join club, unable to relate to and communicated with other students.	Son was kissed by a girl as a prank; the experience confused and horrified him when mother explained the situation.	Although son participated in school clubs, parents were about concerned what he experienced.	Social naïveté made daughter a target for bullies.
Mother believed son's school social experience was negative.	Parents thought son's school social experience was non-existent.	Mother stated that except for social life, son's high school was great.	Son did not share details of friendships; son's social experience was an unknown to the parents.	Daughter had difficulty distinguishing between <i>friend</i> and <i>acquaintance</i> .
Son was picked on by others and called "Sped".				Daughter's school social experiences were negative; mother recalled many experiences where daughter was teased or ridiculed.

Identified Commonality #3

The importance of establishing a relationship with their child's school was present in the responses of all the parents. Parents said that communication and parental involvement were important, as they spoke of the relationship they had established with their child's school. P1 brought up the importance of communication two different times during her responses to the interview questions.

R: "Is there anything you would like to share about your child's educational experience in school?"

P1: "Just that there was never enough— past elementary school—I never felt like there was enough communication with me as far as how he was doing and what problem areas he may have had. And when you have a child that doesn't speak up and usually doesn't tell you things until after they've already happened—I think there needs to be more interaction between the parent and the teachers."

R: "Describe your experience participating in your child's IEP meetings."

P1: "In general, I thought they were positive because it was one of the few times that you get to have one-on-one with the teachers and with them telling you 'he's doing good in this,' or 'he needs more work on that.'"

P2 mentioned the frustration of trying to help their son with home learning assignments, and due to his lack of organizational skills not having the assignments written in his agenda. P3 indicates Internet pages and e-mail contact, which was just beginning to be used at the time their son was in high school, was very effective.

P2: “Sometimes it’s so frustrating, you wish you could be in the classroom with them...However, to the high school credit they did have- whenever it was working- the Internet connection... Our little girl is excellent because she’s in middle school now. We get contact- we get information all the time and e-mails from the teachers continuously, Which wasn’t available at the time at that extent. And it’s very helpful, actually.”

P3 recalled an incident when there was a power failure at school, and her son believed, erroneously, that he had been the cause of it; having close communication with someone on school staff was important.

P3: “So Ms. B had to call me because he thinks he did it- and the teacher said that it just happened... But there’s, you know, always communication with Ms. B or Mr. H to me- to call me because I told them if there’s something they need- if he needs me- just to call me.”

R: “Communication was important?”

P3: “It was important to me.”

P4 could not indicate whether their son’s social experience in school was positive or negative; their son did not provide details or information to the parents. The IEP meetings were beneficial to P4 because of the opportunity to talk with the teachers about areas where S4 needed help, since that information was not forthcoming from their son.

R: “Would you characterize your son’s social experience in school as mostly positive or mostly negative?”

P4: "I would probably say we don't know. That's the problem is that we don't know the results- we don't know what he accomplished. I would say positive, but it's an unknown for us."

R: "Describe your experience in the IEP meetings."

P4: "Very good, because it brought up things that he needed help."

P5 had the most to say about communication between home and school. First, she mentioned speaking with the Kindergarten teacher on the second day of school when there was a problem with S5 walking in line.

P5: "I said, 'Okay, what's the problem?' She says, 'Well, she kept getting out of line, like the whole time we're walking to the cafeteria.' And I said, 'Oh. How about this. Today why don't you say: S5, we're going to walk in line, you're going to get in line, and we're going to stay in line until we get to the cafeteria and until you get your lunch. Then you can sit down.' She goes, 'Well, that's what I said.' I said, 'Did you say you had to stay in line the whole time?' She goes, 'Well, no, the kids know...' I said 'She doesn't. You're assuming that she knows that's what she meant, but you can't make that assumption.' ... And when I went to pick her up that afternoon she [teacher] goes, 'It worked! That was so easy!'"

P5 shared her perspective of the teacher characteristics that were effective in helping S5 achieve her academic goals.

P5: "We were fortunate that there were enough teachers that would read about it [Asperger's syndrome]. I see S5's very bright, but she's not like the other kids, and that's not always a bad thing. But you know, they wanted to learn about it, and then do what

they could to maybe change things to help her. So the teachers that were going to learn about Asperger's and talk to me as a parent, saying 'Here, this happened. What can I do to – any suggestions of what could be done to help this situation?' Good communication. Yeah."

And finally, P5 shared her thoughts on the importance of a teacher assigned as a liaison between the home and the rest of the school faculty.

P5: "In the school system it was very good to have a 'go to' person. Not just for her, but for me, as well, that understood the Asperger's. And so in our case it was Mr. Q. If there was an issue going on, whether it be academic, social, anything that I got wind of, I could e-mail him or call him, and he was always very open. And then he would right away check into it and find out what was going on...I think as a parent- that was very valuable to me to know there was one person I could contact that would then do the thing they needed to do...So I think having a person in the school that understands it- can be a liaison between the child and the parent and the rest of the staff. I think that's important."

Parental involvement was evident in the affirmative responses to the questions asking whether the parent(s) participated in the IEP meetings and Transition meetings. Involvement of the parents went beyond that, throughout their child's educational experience. P5 was involved with educating S5's teachers about Asperger's syndrome, and how to work effectively with S5 in the mainstream environment.

P5: "I think nowadays, hopefully, there's more education to staff and teachers about high functioning autism. And again, when we started this whole journey it really wasn't. And

we had to do a lot of the explaining and the educating. And I always felt as a parent I didn't really want to have to be in that role because I think- there's a sensitivity there of feeling like 'You're just saying that because it's your kid.'"

P4 stated explicitly the importance of parental involvement.

R: "Is there anything else you would like to tell me about your involvement in your child's academic and social experiences in public school?"

P4: "The only thing I would probably say is very, very important is the involvement of parents with children. Very important. We, I think we have tried- I don't know if we have succeeded but we have tried to be involved in everything...As I said, parents have to be very involved, yes. Have to be involved. It's very important."

In response to the same question, P2 responds,

P2: "We kept in touch with the school. You know, through -mails and being there at the school whenever we had the meetings."

The commonalities found in the responses of the parents suggests a theme of establishing communication and a relationship between the home and the school. Sub-themes of the importance of communication and parental involvement are suggested components of establishing this relationship. Table 7 provides a brief summary of the parents' responses which support this theme.

Table 7: Parents’ Responses Supporting Establishing Communication and a Relationship Between the Home and School

P1	P2	P3	P4	P5
At least one of the parents participated in all son’s school meetings	Parents participated in all son’s school meetings	Parent participated in all son’s school meetings	Parents participated in all son’s school meetings.	Mother participated in all daughter’s school meetings.
IEP meetings were important because of time available to talk with teachers.	Communication with school via e-mail and telephone focused on academic support.	IEP meetings were important, and there was good communication with the teachers.	Parental involvement is very, very important.	A teacher liaison between parents and staff was helpful to handle problematic situations before it escalates.
Limited communication from school was problematic to the mother.		Special education department chair maintained good communication with mother.		

Identified Commonality #4

Four of the five parents participated in the Transition meetings for their child, which introduced them to the Office of Vocational Rehabilitation and mentioned other services that were available to their child once he/she graduated from high school. P5 did not have a Transition meeting since at that time S5 was on a 504 Plan, and did not have an IEP in place. Three of the four parents expressed dissatisfaction with the Transition meeting and with the school’s ability to prepare their child for a post-secondary experience. All the graduated students in this study went on to college.

R: “Describe your experience in meetings for your child’s transition into post-secondary school educational or vocational opportunities.”

P1: "It wasn't that it was negative, per se. But it almost seemed like they wanted us to push more toward vocational, versus going to college... It was almost like they weren't encouraging enough for the fact that he wanted to go to college... And that was not something that I was really expecting."

Three parents mentioned that their child's school experience did not prepare them well for post-secondary educational opportunities because of the difference between high school and college.

R: "How well do you feel your child's school experience prepared him for post-secondary opportunities such as additional education or employment?"

P1: "Not very well. But I think that- you know for most kids the difference between high school and college is very major. Even if you don't have anything, you know, wrong with you."

P2: "Not well at all. I think he was not prepared. I mean- I realize that academically he knew the subjects. But he had no idea what he was going to face in higher education, absolutely no idea. It was like, you know, if you transplant to the planet Mars, for him he was totally, totally, completely lost. And, we should have done something to prepare him for that. And, we didn't. And, you know we were just kind of bumbling around, trying to come up with an answer for questions we didn't even understand ourselves... He was set up to fail. There was no way for him to make it. But it was a learning experience for all of us."

P4: "That post-secondary idea- university, college- is very different for anybody. Not only those with disabilities, anybody... But what I was starting to tell you is that

university is different. I think there should probably be other courses similar to college that should be given in high school... It takes time to adapt to everything. They should have maybe some type of course, or something, to show the students how college is.”

Based on the commonality of parents’ responses, a theme of preparation for post-secondary experiences is suggested. Table 8 provides a brief summary of the parents’ responses which support this theme.

Table 8: Parents’ Responses Supporting Preparation for Post-Secondary Experiences

P1	P2	P3	P4	P5
High school did not prepare son well for college; the differences between high school and college are very different	High school did not prepare son well for college; it was vastly different and he was lost	School prepared son well for college, and communicated well with parent	High school and college are very different; school did a good- but not excellent- job of preparing son for college	Daughter chose the college she wanted to go to; no support for transition due to 504 Plan (not IEP)
Mother was disappointed in the transition meeting; she felt son was being pushed into a vocational setting rather than college.	Parents did not follow through with services from Vocational Rehabilitation.			

Research Question Two: Outliers of Parent Responses

Although commonalities were detected in the parents’ responses there were, however, responses made by parents that were noteworthy and lacked commonality with the other parents’ responses.

When parents were asked whether having an ASD affected their child's ability to learn, four of the five parents indicated that having an ASD negatively affected their child's ability to learn. P4, on the other hand, said:

P4: "No, definitely not. On the contrary, I think being an autistic child, some of the things he has is the memory is probably more developed than other kids. He has a good memory."

P4 also did not mention a specific learning accommodation that was helpful to their child, only that they did not call attention to their son's ASD diagnosis, and treated him like any other child:

P4: "I think she [sister] was a big factor in S4's accomplishment in what he is right now. She didn't know S4's autistic problem until probably middle school—she didn't know—it was her sophomore year in high school when she found out. So it was by not knowing he was treated like any other regular person in the house. And that, she helped especially at home, you know, quite a bit. So when you say learning accommodation, we say he was treated like any other child—and normal child, if you put it that way."

P5's advocacy for her daughter to be in mainstream settings, and her efforts to inform teachers of Asperger's syndrome, was distinct among the responses of the other parents.

P5: "The person in charge of staffing for the county was insistent that she be at a minimum in a varying exceptionalities class. I was very, very adamant that I wanted her mainstreamed, and I wanted her mainstreamed at the XX Preschool laboratory, in particular. The woman made a remark at the meeting that I thought was very inappropriate, which was this, and I don't think any professional should ever say this:

'Well, if it were my child, I would put her in a VE class or an autism class.' And, all I can

say is, with my daughter graduating from college tomorrow, good thing it wasn't! And, I thought about, if she's still with the county, sending her S5's graduation announcement...I think for S5, mainstream was the right thing. I really do. Because we took care of some of the other things through insurance. A lot of it we paid for ourselves. But I think that some of the things can— you can get all these services without having to be in a self-contained ESE class. You can get, if you need, therapy, you can get all those things.”

As with the outlier responses of the graduated students, the unique responses of the parents in this study express areas of importance to that parent(s).

Research Question Two: Summary of Identified Commonalities and Themes

Commonalities among the parents of graduated students with ASD suggest that a) their child experienced learning difficulties due to having an ASD; b) their child had difficulty making friends and participating in social experiences; c) establishing a relationship with the school incorporating communication and parental involvement was important to the parents; and, d) preparation for post-secondary experiences is necessary. These commonalities suggest the following themes: a) learning challenges ; b) difficulty making friends; c) establishing communication and relationship between home and school; and, d) preparation for post-secondary experiences.

*Research Question Three: Comparison of Graduated Student Responses
and Parent Responses*

This section addresses the third research question: Are there common themes between the graduated students' lived experiences and the parents' lived experiences? If so, what are the commonalities found in the data? First, a comparison of the responses of each graduated student with his/her parent will be presented. Next, the commonalities of responses and identified themes of the two subject groups, graduated students and parents, will be compared. Following the presentation of the comparisons, a discussion of the inter-rater agreement in finding commonalities of responses will be provided. The chart found in Appendix H was used to compare the responses of the groups, as well as the individual graduated student with his/her parents.

Comparison of Graduated Student (S1) and His Own Parent (P1)

S1 and P1 had similar responses in 12 of the 20 subsidiary questions that were presented in the interview. For the first set of subsidiary questions for Guide Question #1 S1 and P1 had general agreement that S1 felt more successful in classes or learning environments where teachers were "understanding" or "caring". The remaining questions in that section, while dissimilar, did not contradict each other. There was strong similarity in responses for all the subsidiary questions of the Guide Question #2; however, S1 tended to state his responses more emphatically, and with stronger language.

R: "Describe your experience as you went through graduation."

S1: “It was nerve-wracking and sweaty, and not a very pleasant thing. I just wanted to get it over with and go home.

P1: [later, after recalling that S1 had participated in graduation] “...social situations scared him.”

R: “Would you characterize (your /your child’s) social experiences in school as mostly positive mostly negative?”

S1: “To put it bluntly, mostly negative. The number of humiliations, embarrassments, and misunderstandings vastly outweighed the positive experiences.”

P1: “I think it was negative for him for the most part.”

R: “Is there anything else you would like to say about (your/your child’s) social experiences in school?”

S1: “That it was hellish and I never want to go through that again.”

P1: “No, I just- I tend to think he didn’t have that many social experiences in school.”

Both S1 and P1 stated that S1 was diagnosed with an ASD at a later age, and that limited his opportunity to participate in a social skills class. S1 and P1 agreed that S1’s social experiences in school were negative; he had great difficulty making friends; and, no support was provided by the school to assist S1 through the anxiety he felt in social situations. Regarding the subsidiary questions associated with Guide Question #3, S1 and P1 agreed that they had both participated in IEP meetings and Transition meetings, and both mentioned that high school and college are very different.

R: “How well do you feel (your/your child’s) school experience prepared (you/him) for post-secondary opportunities such as additional education or employment?”

S1: “I’m not entirely sure, but you can’t really compare the grade school experience with the college experience. They are too different.”

P1: “Not very well. But I think that, you know, for most kids the difference between high school and college is very major.”

Reviewing the summaries of S1’s and P1’s responses and the field notes, commonalities expressed indicate they both believed the social aspects of school negatively impacted S1’s ability to participate in the educational aspect of school, and more significantly the social aspect of the school experience. Both S1 and P1 mentioned S1’s high intellect in different ways, but recognized that the intellect could not overcome his ability to socialize and make friends. During her interview, P1 mentioned S1’s depression and anxieties. While S1 was being interviewed, the depression and anxiety that P1 spoke of was evident in his body posturing (hunched over, sweatshirt hood over his head and falling lower onto his face when talking about social issues) as well as in the lengthy pauses and labored efforts to speak, and brief responses.

Comparison of Graduated Student (S2) and His Own Parents (P2)

S2 and P2 had similar responses in ten of the 20 subsidiary questions that were presented in the interview. Both S2 and P2 agreed that having an ASD negatively affected S2’s ability to learn, however, they differed in the way in which ASD impacted S2’s learning.

R: “Did having an autism spectrum disorder affect (your/your child’s) ability to learn? If so, how?”

S2: “Yeah. When they’re trying to explain a project and it has to be done a certain way, I tend to not understand the details—a lot more details.”

P2: “Yes. A child with this type of disability has two main conditions, as far as our experience is concerned. One is organization. Which is a must for any student- to be able to organize information that he or she is going to require. To do the test, to do the homework, and so forth and so on. The other is the social aspect of it. Basically they have no social life whatsoever because they are not understood, they do not understand the other children, and they have a problem with the body language and recognition. So all of this affects their interaction with other students where he or she may learn- not only behavior, but learn other things even about the curriculum from other students.”

Both S2 and P2 mentioned that auditorium classes were difficult for S2, but in response to different questions.

R: “You have had many academic experiences throughout your years in school. Please tell me about a learning experience that you vividly recall.”

S2: “Well, it’s a bit embarrassing to mention, but it’s the only one that I can come to my mind. I don’t think this has anything to do with my learning disability but my history class, it took place in the auditorium, and usually we watch movies that represents the information. And it was a dark room, and this was the first class I have in the morning. So I always have a tendency to just- and the room is not all that cold at all- it’s warm. So I tend to fall asleep during the educational movie.”

R: “Describe the classes or learning environments that were most challenging for your child.”

S2: “I think the larger classroom settings—the auditorium type classrooms. It’s a nowhere land. It’s impossible.”

The remaining responses to questions associated with Guide Question #1, while dissimilar, did not contradict each other. As with S1/P1, the majority of S2/P2's similar responses were in conjunction with Guide Question #2. Both S2 and P2 agreed that S2 did not have a social skills class, and that he did not want to participate in school social experiences, except for high school graduation. Both S2 and P2 acknowledged that there was no help from school personnel to assist with S2's participation in social experiences. When asked to recall a social experience that they vividly recalled, S2 mentioned a positive experience, while P2 related a negative experience.

R: "Is there a social experience (you/your child) in school that you vividly recall? If so, please describe what you recall.

S2: (smiling) "There was this thing we did for a project for school which the art magnet program switched to different classes for a week to learn- to see the other ones... I had a lot of fun with that and since then I've been with these guys. The pictures are hilarious."

P2: "The experiences were very negative. There was a little girl in high school who was part of the program, 'cause I know because of the Program Specialist knew her well also, that developed that kind of, well, love relationship. But it went sour, didn't work out. So that's the only one I can recall."

Regarding the subsidiary questions associated with Guide Question #3, S2 and P2 agreed on three of the responses, and the remaining responses could not be compared. Both S2 and P2 participated in IEP and Transition meetings, and both felt that high school poorly prepared S2 for the post-secondary educational experience. Both S2 and P2 mentioned that P2 wished for more social experiences in school, but S2 just didn't want them.

R: “Do you remember a time when (you/your parents) wanted something for your school social experience in which (you were/your child was) not in agreement?”

S2: “They didn’t make me, but they did ask me if I should go, and stuff. I didn’t go.

Like I said, I don’t do Proms or any of that group stuff.”

P2: “Yes, there has been. Because I’m one of those that pushes for that—and he says, ‘No, Mom.’ No, I don’t push him.”

P2 had previously made the statement, that was supported in the above assertion:

R: “Is there anything else you would like to say about your child’s social experience in school?”

S2: “I wish there would be a little more of them. Yes, yes.”

Looking at the summaries for S2 and P2, as well as the field notes that were written, evidence suggested that both S2 and P2 knew of S2’s artistic talent, and wanted more post-secondary experiences in that field. S2 was very comfortable with a limited social life, associating with others who had similar interests. P2 wished there had been more social experiences. Both S2 and P2 believed that high school in general was a positive experience for S2.

Comparison of Graduated Student (S3) and His Own Parent (P3)

S3 and P3 had similar responses in ten of the 20 subsidiary questions asked in the interview. S3 and P3 had three similar responses out of the eight subsidiary questions for Guide Question #1, however, those responses that were dissimilar did not contradict each other. Both S3 and P3 believed that academic experiences requiring social participation affected S3’s ability to learn.

R: “Did having an autism spectrum disorder affect (your/your child’s) ability to learn? If so, how?”

P3: “Yes, I do. It affects his ability to learn socially. That was his number one problem, socialization.

S3: “There are times when students will need to participate in projects together, and they will need to know how to properly deal with other students.”

R: “Did the social aspect affect your ability to learn?”

S3: “At least for me it was. I don’t know if that experience applies to other students with high functioning autism.”

S3 continued to list other challenges he had to learning, which are typically associated with students with ASD: the ability to concentrate, and difficulty adapting to new routines. When asked about assistance for home learning assignments, it was evident that S3 focused on the academic aspect of the learning activity, while P3 had a more global understanding of what was needed to complete the assignments.

R: “What help, if any, did (your parents/you) provide for home learning assignments?”

S3: “As far as academics went, they weren’t really able to help me that much mostly because of their limited academic background.”

P3: “He usually does his own homework, but I’m just there to support him and just to make sure that he manages his time doing his homework, and make sure that he’s on time doing his homework.”

When asked to tell about a learning experience that they vividly recalled,

S3: “ I’m trying to go over each year that I’ve been to- I try to go over each year that I’ve been through, and right now nothing seems to come to mind.”

P3 recalled when S3 performed a Shakespearean soliloquy in his English class, using her bathrobe as a prop, and according to reports from his classmates, S3 did an amazing job.

P3: “And we were talking about it with my husband, and I said ‘I can’t believe this! Look at this comment from all the classmates! And one classmate of his says maybe you’re going to the acting class.’”

S3 and P3 agreed on four responses of the subsidiary questions associated with Guide Question #2. Both acknowledged that S3 had not taken a social skills class, and that S3 was a member of several clubs and honor societies in school. A qualitative distinction was evident, however, in their responses to the question about S3’s participation in clubs and activities:

S3: “Being a part of these clubs and societies, I needed efforts to get to know other people a bit more. I was – unfortunately I still felt a bit detached. I wanted my name to be more known among the other members of these clubs or these activities or societies.”

P3: “I was very happy [about his participation] because he’s really grown in his socialization and I always encouraged him to participate and I encourage him to join the clubs. He doesn’t want to in the beginning, but I think that you have to try.”

S3 indicated that personnel in the special education department assisted his participation in some of the school social activities, while P3 believes that it was her encouragement that got her son to participate in the activities.

R: “What help did school personnel provide, if any, for (your/your child’s) participation in social activities?”

S3: “School personnel that were able to help me most were...the Special Education department...They didn’t help me directly for participation in school activities, but they did help me deal with—they were familiar with my situation so they—I believe these individuals were well equipped to deal with my own personal feelings.”

P3: “No, not really. he just found out that they’re asking for students to participate. And I said go ahead. Any social activities in school you have to go.”

Both S3 and P3 each recalled a social experience that was negative in tone; however, the two experiences were different ones. S3 and P3 had agreement in all but one subsidiary question related to Guide Question #3. S3 and P3 agreed that they attended IEP meetings and Transition meetings, and that these were helpful experiences for S3. S3 and P3 both mentioned maintaining communication with the Vocational Rehabilitation counselor whom they were introduced to during one of S3’s Transition meetings. S3 and P3 believed that high school for college, however S3 indicated he still has uncertainties about what he wants to do. Interestingly, the parting comment for both S3 and P3 stressed the importance of encouragement.

R: “Is there anything else you would like to tell me about (your/your parent’s) involvement in your academic and social experiences in public school?”

S3: “They were always there for me when I needed them... Academic-wise I was taking classes that were beyond their level, but they were always still pushing me and encouraging me to try my best. And that’s exactly what- whether it’s Auties, Aspies, or NTs- or any- whether it’s anybody on this diverse spectrum, regardless of whatever, of who they are, they always need that kind of encouragement just so they can have the drive and motivation to get themselves going.”

P3: "...like I said, he did really well in school. And I really don't have a problem with that. But the social skills, he really needs encouragement all the time. A lot of encouragement. But if I don't do it, he will never do it. That's the most important thing. Encouragement."

Both S3 and P3 were very polite and formal in their presentation for the interview. S3 lacked fluidity in his speech, repeating words and multiple-word phrases throughout the interview. P3's first language is not English, and although she was able to communicate and respond to the interview questions, at times she had to search for the correct words to convey her thoughts. The regard and respect that S3 and P3 have for the people who taught S3 through the years was evident not only in the responses to questions posed in the interview, but also in comments made by S3 and P3 before the interview as the researcher was establishing rapport.

Comparison of Graduated Student (S4) and His Own Parents (P4)

Like S2/P2 and S3/P3, S4 and P4 agreed in their responses to ten of the 20 subsidiary interview questions, and no contradictions existed in S4's and P4's dissimilar responses for Guide Questions #1 and #3. What is interesting, however, is that S4's and P4's responses were unlike responses made by others who participated in this study. For example, when asked whether having an ASD affected S4's ability to learn, other participants in the study answered that ASD negatively affected their ability to learn. S4 and P4 responded:

S4: "I really don't think so. I mean, I believe I have the same capacity to learn as other students. I mean, I pay attention. In fact I believe I pay attention more than other students."

P4: “No. Definitely not. On the contrary, being an autistic child, some of the things he has is the memory and probably developed more than other kids.”

When asked about learning accommodations that were most helpful to S4, the replies were:

P4: “...we say he was treated like any other child—any normal child, if you put it that way.”

S4: “I guess sitting in the front. I prefer to sit in the front than the back...I mean, I never requested the front, I just tried to get to the front.”

S4 states later, in the interview,

S4: “I never told anybody about my, um, I don’t know, I just didn’t want to tell them about it.”

S4 and P4 both indicated that S4 did not take a social skills class in high school, and he did participate in several clubs at school. In reference to assistance provided for S4’s participation in social activities, S4 and P4 differed:

S4: “I don’t think they helped me in that area. They just helped me get the best possible education for my classes.”

P4: “Probably the Agri-Science teacher- I think she helped quite a bit...She was always trying to get S4 involved in these kind of activities. She was encouraging.”

S4 and P4 also differed in their perspective of S4’s ability to make friends.

S4: “For the first two years I didn’t really have any friends. But then during Junior year I decided to, I don’t know- step forth and try to make friends. And so I did.”

P4: “Very difficult. Very, very, very difficult...But he tries, and he has people that care about him, from what I notice.”

Distinctly different from other participant responses, S4 and P4 both characterized S4's social experiences in school as mostly positive:

R: "Would you characterize your social experiences in school as mostly positive or mostly negative?"

S4: "Mostly positive. Well, I tried not to get into any trouble. I focused on my education and make sure my friends were not shady."

P4: "I would say positive, but it is an unknown for us."

The line of questioning relative to S4's involvement in school revealed that S4 and P4 expressed that school had prepared S4 well for the post-secondary educational experiences. Again, this was in contrast to responses of other graduated students and parents.

R: "How well do you feel (your/your child's) school experience prepared (you/him) for post-secondary opportunities such as additional education or employment?"

S4: "I think they prepared me very well. Well, C.R. high school is a good school. Especially when you compare it to most schools around the area."

P4: "Good. Not excellent, but good. High school, yes."

S4 and his parents, along with his sister, presented as a very supportive, cohesive family unit. While P4 recognized the significant social challenges that S4 had in school, S4 felt socially accepted and successful. S4's reluctance to share much of his school experience with his parents seemed to bother the parents, as P4 would respond to some of the questions with phrases such as "He is very independent", "It's an unknown for us" and "We don't know any friends in high school...since we don't know the results, we don't know of anything positive or negative. He

doesn't share.”

Comparison of Graduated Student (S5) and Her Own Parent (P5)

S5 was the only female graduated student interviewed for this research. Responses for the subsidiary interview questions showed S5 and P5 agreed in 12 of the 20 questions. Where S5 and P5 provided dissimilar answers, they did not contradict the other's responses. S5 and P5 both indicated that having an ASD affected S5's ability to learn, but for different reasons:

S5: "...I had trouble with abstract thinking, and I had trouble with art because of my fine-motor problems and handwriting.”

P5: "I think from an academic standpoint, or a cognitive standpoint, I think sensory distractions at times- very, very much so in elementary school, but even until this day she can be distracted by just being in a classroom with other people...And then, of course, the social challenges particularly starting in around middle school affected her learning because of just being in school, being worried about other kids and not feeling comfortable in her classrooms.”

S5 and P5 agreed that having extended time was an important accommodation for S5, but P5 also mentioned that preferential seating and having a pass to see a specific person when S5 was feeling anxious or overwhelmed was important, too.

Both S5 and P5 agreed that S5 had not participated in a social skills class, and had participated in social activities around school. S5 mentioned feeling passive, in the background of the activities:

S5: “But even at the Senior Prom I was kind of in the background. I didn’t dance or anything. And as far as clubs go, well the only clubs I was involved in were Best Buddies, and then most of the parts of my school’s chorus. But even though I was in it, I wasn’t actively involved. I was kind of more passive.”

Regarding S5’s participation in the social experiences, P5 clarified that S5 was assigned to be a mentor to a student with lower functioning ASD in the Best Buddies program. P5 also mentioned that she was concerned with S5’s participation in chorus:

P5: “Best Buddies I thought was fine. A little concerned, I guess, about Chorus, whether she’d be accepted in there. I guess it was always a matter of how she was going to be okay with the other kids.”

Both S5 and P5 indicated that it was difficult for S5 to make friends. S5 indicated that she was always “a loner”, while P5 stated that S5 was ostracized by other girls and had difficulty distinguishing between a friend and an acquaintance. When asked to share a social experience that they vividly recalled, both S5 and P5 shared negative events; however P5’s recollection was more specific and decidedly more negative:

S5: “No, I didn’t really have one [vivid social experience]. I mean there were kids that teased me, if that counts.”

P5: “There’s so many of them... She was set up with a young lady that was her friend for a while- for about six weeks, no, maybe three months. They were inseparable, together all the time. And then the other girl turned on her with a bunch of other girls.”

P5 went on to tell of another incident in which girls smeared applesauce in S5’s long blond hair, and later when the applesauce had dried called attention to S5’s hair, claiming she had lice.

P5: “And, you know, it’s definitely had residual effects to this day. She doesn’t trust people. It’s easier to do on-line courses. It’s easier just to decide she’s not going to meet people. That she’s fine alone...She doesn’t have one person she can call up and say ‘Hey, let’s hang out. Want to watch a movie? Want to do this?’ So, I think it bothers me more than it bothers her. She’ll say it doesn’t bother her, and maybe by now it doesn’t. It bothers her because it’s what she thinks I want. I want her to be happy.”

When responding to the subsidiary questions to Guide Question #3, both S5 and P5 referred to a “go-to” person as a helpful staff liaison for S5 as well as for communication between home and school:

S5: “There was one person I forgot to mention about. He was like this go-to—He was the head of the autism department and he gave me a go-to pass in case I needed to see him for any concerns. And I really liked him a lot. He was kind of educational and he helped me if I had any problems and stuff...I mean he worked with autistic kids, but I was never really part of his class because some of the kids were more lower functioning, and I didn’t really need that.”

P5: “In the school system it was very good to have a ‘go to’ person. Not just for her, but for me, as well, that understood Asperger’s...If there was an issue going on, whether it be academic or social, anything that I got wind of, I could e-mail him or call him and he was always very open. And then he would right away check into it and find out what was going on. Sometimes he could speak to a teacher and, you know, how to nip something in the bud...So I think having a person in the school that understands it- can be a liaison between the child and the parent and the rest of the staff. I think that’s important.”

S5 was distinctive from the other graduated students, not only because she was the only female, but also because she was very concerned about how the researcher judged her through her honest responses. When questions related her social experiences were presented, S5 made comments indicating concern that she would be judged negatively based on her responses. P5 presented as very involved in advocating for her daughter throughout S5's K-12 educational career. P5 expressed pride in her daughter's accomplishments throughout her school career, and especially of the fact that S5 would be graduating from college very soon.

Commonalities of Graduated Student Group and Parent Group

When comparing the commonalities of the graduated students with the commonalities of the parents for each of the subsidiary question, there is general agreement in the response for 15 out of the 20 interview questions. Agreement was noted when two or more participants in each of the group responded similarly. As a group, graduated students disagreed with the parent group on three questions:

- 1.4: What help, if any, did you/your parents provide with home learning assignments?

Two of the graduated students indicated that they had tutors; one said that his parents explained the book; one said that his mom helped but he wasn't sure how; and one student said his parents couldn't help because of their limited academic background. In contrast, four of the parents responded that they helped their child through providing structure and guidance; one parent indicated that tutors were provided.

- 1.7: You/your child have/has had many academic experiences throughout your/your child's years in school. Please tell me about a learning experience that you vividly recall.

Three graduated students said they had no particular recollection of a learning experience, or in the case of S1, his memory of one was repressed. One student had a positive recollection of a learning activity, and one had a negative recollection of a learning activity. By contrast, four of the parents shared a recollection of a positive learning experience for their child.

- 2.5: Would you characterize your/your child's social experience in school as mostly positive or mostly negative?

For this question, two parents indicated that their child's experience was negative; and one parent indicated that was non-existent; one parent said it was probably positive; one parent indicated it was mostly positive. Two of the graduated students said their social experience was neutral; one indicated his social experience was negative; one indicated his social experience improved during high school; and one said his social experience was positive.

Table 9 provides information about general agreement or disagreement for each of the subsidiary questions asked in the interview. The table compares each graduated student to his/her parent(s), as well as the graduated student group to the parent group. When two or more in each group made similar statements for a question, it was noted as a commonality. If both the graduated student group and the parent group had commonality for a question, then agreement between the groups was noted. Cells containing dashes indicate that agreement of responses could not be determined.

Table 9: Agreement of Responses Between Graduated Students and Parents

Question	S1/P1	S2/P2	S3/P3	S4/P4	S5/P5	S/P
Guide Question 1: What was your educational experience as a (student /parent of a student) in an urban public school system						
1.1 Did having an autism spectrum disorder affect (your/your child’s) ability to learn?	Yes	Yes	Yes	Yes	Yes	Yes
1.2 Describe the classes or learning environments in which (you/your child) felt successful.	Yes	Yes	--	No	--	Yes
1.3 Describe the classes or learning environments that were most challenging for (you/your child).	No	No	No	No	No	Yes
1.4 What help, if any, did (your parents/you) provide with home-learning assignments?	Yes	No	No	Yes	Yes	Yes
1.5 What learning accommodations do you believe to be the most helpful?	No	No	Yes	No	Yes	Yes
1.6 Describe the characteristics of those teachers that were most effective in helping (you/your child) achieve (you/ his-her) academic goals.	Yes	No	No	No	Yes	Yes
1.7 Tell about a learning experience that you vividly recall.	No	No	No	--	No	No
1.8 Is there anything else you would like to share about (your/your child’s) educational experience in school?	No	No	Yes	--	--	--
Guide Questions 2: What was (your/your child’s) social experience as a student in the public school system?						
2.1 Did (you/your child) participate in a social skills class?	Yes	Yes	Yes	Yes	Yes	Yes
2.2 Did (you/your child) participate in any clubs and/or after school activities, including senior events?	Yes	Yes	Yes	No	Yes	Yes
2.3 What help did school personnel provide, if any, for (your/your child’s) participation in social activities?	Yes	Yes	No	Yes	Yes	Yes
2.4 Was it easy or difficult for (you/your child) to make friends?	Yes	Yes	Yes	Yes	Yes	Yes
2.5 Would you characterize (your/your child’s) social experiences in school as mostly positive or mostly negative?	Yes	Yes	--	Yes	--	No

Question	S1/P1	S2/P2	S3/P3	S4/P4	S5/P5	S/P
2.6 Is there a social experience (you/your child) had in school that you vividly recall?	Yes	No	Yes	No	No	Yes
2.7 Is there anything else you would like to say about (your/your child/s social experience in school?	Yes	Yes	--	Yes	--	Yes
Guide Question 3: What do you remember about involvement in (your/your child's school experience?						
3.1 Did you participate in (your/your child's IEP meetings?	Yes	Yes	Yes	Yes	Yes	Yes
3.2 Was there a time (your parents/you) requested an academic and/or learning accommodation in which (you/your child) were not in agreement?	--	--	--	Yes	No	Yes
3.3 Do you remember a time when (your parents/you) wanted something for (your/your child's) school social experience in which (you were/your child was) not in agreement?	No	Yes	No	Yes	Yes	Yes
3.4 Did you participate in meetings for transition into post-secondary school educational or vocational opportunities?	Yes	Yes	Yes	Yes	Yes	Yes
3.5 Is there anything else you would like to tell me about (your parent(s)/ your) involvement in (your/your child's academic and social experiences in public school?	--	--	Yes	No	Yes	--
S-P Agreement	12/20	10/20	10/20	10/20	12/20	15/20

Three themes were detected in the graduated student responses, which ran parallel to the three guide questions for the interview. The themes suggested for the graduated students' responses were: a) learning challenges due to ASD; b) challenges with making friends; and, c) involvement in their educational process. Themes detected in the parents' responses also indicated learning challenges associated with having an ASD, and challenges with making friends. Other themes detected in the parents' responses pertained to the a) relationship between school and home, with sub-themes of communication and parental involvement; and b)

dissatisfaction with preparation for post-secondary school activities. Table 10 provides a brief synopsis of the identified themes for the Graduated Student Group and the Parent Group.

Table 10: Identified Themes of Graduated Student Group and Parent Group

Group	Theme 1	Theme 2	Theme 3	Theme 4
Graduated Students	Learning Challenges	Challenges Making Friends	Involvement in their Educational Process	
Parents	Learning Challenges	Challenges Making Friends	Communication and Relationship between home and School	Preparation for Post-Secondary Experiences

The Brief Summary and Commonalities of Graduated Students' Responses (Appendix M) and Brief Summary and Commonalities of Parents' Responses (Appendix N) may be viewed for specific information about the identified commonalities for each of the groups on each of the 20 subsidiary interview questions.

Inter-rater Agreement

To determine the reliability of the ratings for the commonalities of responses between the graduated student and his/her parents, a simple percentage of agreement, as well as a Cohen's kappa statistical analysis, was applied. There were 20 subsidiary questions asked during each interview with 10 interviews conducted in all: five graduated student interviews and five parent

interviews. In this analysis, responses to a total of 120 questions were rated for agreement or disagreement: the graduated student's commonalities compared to the parents' commonalities, (20 responses); then each of the five graduated student's responses compared to his/her parent's responses (20 responses for each of the five). Inter-rater agreement correlations for research purposes should be greater than .70 (Wood, 2007).

An expert focus group member was used as the independent rater. The 120 responses were evaluated using a three point method to indicate "agreement", "disagreement" or "cannot be determined". The researcher and independent rater showed agreement in 115 of the 120 responses. Calculating a simple percentage correct of agreement, this corresponds to approximately 96% inter-rater agreement. Using SPSS (2006) to calculate a Kappa statistic, the inter-rater agreement was .907, or approximately 91%. This shows high inter-rater reliability, and provides strength to the evaluation of agreement or disagreement between respondents (Wood, 2007). Appendix Q provides the SPSS Kappa calculation output.

Summary

Chapter 4 presented the data obtained in this research, beginning with the validation of the interview questions by the expert focus group. Interview data was explicitated, and commonalities between graduated students and the parents were detected. Themes describing learning challenges, challenges with making friends, and involvement in the educational process were extracted from the graduated students' responses. Similar themes of learning challenges and difficulty making friends were also described in the parents' responses. Additional identified themes included relationship between the school and home and parental involvement.

Outliers of responses within the graduated student group and within parent group were noted. Commonalities of responses between the graduated student group and the parent group were compared, and notable areas of agreement or disagreement were highlighted. Subsequently, comparisons were made between responses of the graduated student with his/her own parent, with statements of agreement or disagreement highlighted for each unit. Finally, results of a Cohen's kappa statistical procedure for inter-rater reliability of the evaluation of agreement/disagreement of responses was provided.

CHAPTER 5

SYNOPSIS, INTERPRETATIONS, AND RECOMMENDATIONS

Chapter 5 includes an overview of the research, and an interpretation of the data relative to current literature on ASD. Chapter 5 also presents implications of this research on policies and procedures for meeting the social and educational needs of students with ASD. Suggested practices for working effectively with the parents of students with ASD in the public school setting are included, as well.

The purpose of this qualitative study was to discover the lived experiences of graduated students who have an ASD, as well as the lived experiences of their parent(s) through their child's education in an urban public school setting. Chapter 5 includes a brief synopsis of this study, followed by summaries and interpretations for each of the three research questions. Implications of this research on educational policy and practice with students with ASD will be followed by recommendations for future research.

Synopsis of Research

Through the use of an expert focus group, standardized interview questions were established which inquired about the lived experiences of graduated students with ASD and their parents through their education in an urban public school district. Incorporating phenomenological research methodologies, summaries and explications of the participants responses were made. Commonalities of responses to the interview questions among the graduated students and among the parents gave rise to broad themes. Similarities and

differences in responses between the graduated students and his/her parent(s) were investigated.

Summary and Interpretation of Research Findings

Research Question #1

Billington (2006) argued that any understanding that we, as professionals, might have of the difficulties of a child with ASD is dependent on our ability to have insight or understanding of the child's experience. Therefore, the first research question explored the lived experiences of students with ASD who have graduated from a large urban public high school with a standard diploma since June, 2005. From the interview data, commonalities and themes of graduated students responses were explicated. Three themes were discovered in their responses, and the themes corresponded to the three guide questions which structured the interview.

Graduated Students: Identified Theme #1

The first identified theme involved learning challenges for students with ASD. Learning challenges, even for higher functioning students with ASD is well documented in recent research. The areas of impairment most frequently noted are in communication and social skills (Sansosti, Powell-Smith, & Cowan, 2010; Thede & Coolidge, 2007; Tsatsanis, 2004; Tsatsanis, Foley, & Donehower, 2004). Listening to the responses of these high functioning graduated students in this research corroborated those areas of impairment, and also gave greater detail about the impact of ASD on their daily learning.

Graduated Students: Identified Theme #2

The second identified theme found that the challenges students have making friends. While children with ASD on the higher end of the spectrum, those with HFA or AS, display a greater interest in making friends than those on the lower end of the spectrum, a variety of social impairments prevents them from being as successful as they would like to be (Sansosti, Powell-Smith, Cowan, 2010). Adolescents with AS report greater levels of loneliness than their neurotypical, or non-ASD, peers. As a result, increased levels of depressive symptoms are observed in students with the ASD (Whitehouse, Durkin, Jaquet, & Ziatas, 2009). Yet again, responses of the graduated students in this study supported the abundance of research that documents challenges for students with ASD in making and establishing friends.

Graduated Students: Identified Theme #3

The third identified theme emerged from the graduated students' involvement in their educational process. Negligible information is available in published research about the involvement of students with ASD in their educational decisions. Special education program specialist P. Hanson (personal communication, December 2010) stated that high school students with high-functioning ASD have the right to share their opinions about decisions that are made regarding their future. Too often decisions are made for the student; without buy-in from the student, the decisions become imposed. Graduated students in this research participated in their IEP and Transition meetings. Even though S2 was not comfortable participating in such meetings, all graduated students stated that they found the meetings useful in accomplishing their

educational and career goals.

Graduated Students: Discussion of Findings

Separating the learning challenges from the social challenges that students with ASD face was difficult for the graduated student subjects. These concepts, learning and socialization, co-exist in public school settings. Statements made by the graduated students intertwined their learning and social challenges along with their involvement in their school experience; therefore, interpretations of the thematic findings are presented collectively.

Clearly, S1's learning was impacted by his social anxieties. He mentions being challenged by classes where he was "forced to socialize against my will" and school being "hellish." The anxiety evident on S1's face and in his body language throughout the interview was palpable. That S1 was capable of learning in spite of the anxieties was evident in his graduation from high school and attendance in college; yet, the effort that S1 expended to accomplish this through his anxieties is almost incomprehensible to a neurotypical. In fact, S1 made the statement that "as neurotypicals, they never fully can" understand how difficult things were for him in school. Research by Billington (2006) supported S1's statement, and this explicitation of S1's experience in school.

S5 was more specific about learning challenges due to having an ASD. She mentioned difficulty with abstract thinking, fine-motor tasks, and the impact low grades had on her self-esteem. Infused into her statements of learning challenges, S5 mentioned being made fun of and judged by others due to her difficulties. S5 recalled doing a project for a social studies class, but because she was not comfortable giving an oral presentation in front of the class she was given a

bad grade. The project S5 completed was on autism, a subject with which she is intimately familiar. Beteta's research (2009), as well as Sinclair's first-hand account (2004) supported the explications of S5's school experiences.

S2 stated that he had difficulty with project-based learning, assignments in which the requirements were not specific. S2's interest was so strong that he went to a private university, which focused on digital arts and computer animation, for almost a year. He did not continue after the first year, and attributed his lack of success at that university due to lack of exposure to specific computer graphics applications while he was in high school. S2's negatively tinged comments about his academic ability concurred with comments made by subjects in Humphrey and Lewis' research (2008). Consistently through his interview S2 made statements indicating that as long as he was surrounded by a subject that he likes (art and computers), and with people who have similar interests, then he is satisfied. The times when S2 was most frustrated occurred when he did not get the type of computer graphics instruction that he was led to believe he would get. S2's ability to focus and achieve in his area of interest is supported in the documentary by Gold (2009). Continued support and structure for S2's learning in project-based learning tasks could, however, help S2 reach his maximum potential in this area (Frea, 2010).

Two of the students mentioned preferential seating as an important learning accommodation. Once again, this learning accommodation appeared to be connected to the social challenges that students with ASD face in the public school setting. S3 mentioned that being isolated from others helped him complete what needed to be done in his classes. S4, who stated that having an ASD did not impact his learning in a negative way, did indicate that he preferred to sit in the front of the classrooms. While S4 did not mention the reason why he

preferred sitting in the front, sitting in front would block from his view most of social aspect of the classroom environment. This hypothesis was supported in S4's and P4's statements of limited friends. S4 seemed to have been able to compartmentalize the learning aspect of school from the social aspect of school. S4 felt successful academically, and believed that he went to a good school that prepared him well for post-secondary educational opportunities. The National Institute of Mental Health (NIMH, 2005) document on ASD supports the use of accommodations as a treatment option for integrating students with ASD in mainstream settings.

Having extended time was another learning accommodation that was mentioned as a helpful for four of the graduated students; however, one of the students mentioned later in the interview that they disagreed with their use of extended time because it made them different from their peers. S3 stated that he remembered feeling uncomfortable having extended time because he might then feel inferior to his classmates. He didn't want to appear different, even if the learning accommodation would help him be more successful. The suggestion that having accommodations made students feel different from their peers was supported by statements from three of the parents (P2, P3, and P4) as well as by phenomenological research by Humphrey and Lewis (2008).

A less frequently cited impact of ASD on learning and social opportunities was their motor clumsiness. Research by Thede and Coolidge (2007) stated that evidence of motor clumsiness exists in 94% of children with AS and 80% of children with HFA. Statements from three of the graduated students in this study supported Thede and Coolidge's findings. S1 said that his participation in P.E. was "nothing more than a public embarrassment". S3, who was very high achieving in his academic coursework, vividly recalled being "picked last and picked on by

other students” in his P.E. class. S5 recalled other kids making fun of her because she was uncoordinated and couldn’t even kick a ball. Apparently motor clumsiness existed, not only as a deficit in and of itself, but also as an impact on students’ social success in school. Students with ASD, who already faced significant challenges in establishing and maintaining friendships, had an added burden when their motor clumsiness made them a target of ridicule, or at the very least rejection, by their peers.

All students in this study indicated that they participated in their IEP meetings and their Transition planning meetings. S5 did not have a Transition planning meeting, per se, but instead she did make her own decision about the university that she wished to attend after high school. The transition to post-secondary educational opportunities was apparently stressful: two of the graduated students and three of the parents mentioned that college/university is very different from high school, and that more should be done to adequately prepare students with ASD for this transition. VanBergeijk, Klin, and Volkmar (2008) posited that carefully planned transition experiences are imperative for a success in college and university settings.

Limited support for the graduated students’ social skills and school social experiences was evident in the graduated students’ responses. Only S3 and S5 recalled having someone that they could go to when they had difficulty. S5 said she had a pass for a “go-to” person who helped her when she had problems. S3 said he went to the SPED department chairperson to get help when he needed it. None of the students had a social skills class. Nor was there a proactive process in place to assist the students with their participation in social experiences. As a result, two of the students did not participate in any school clubs or activities other than graduation; two other students participated, but felt detached from his/her peers. This begs the question that,

while so much was done proactively to accommodate the students' learning, what proactive measures were being implemented to accommodate the students with ASD's social success? Simpson, de Boer-Ott, and Smith-Myles (2003) cited that research had validated guidelines and interventions that would enhance students with ASD's social skills, yet the implementation of such is evidently lacking.

Research Question #2

Whether the graduated students in this study were cognizant of it or not, evidence from the interview responses clearly indicated that parents provided on-going and continuous support for their child's social and educational experiences. Similar to a qualitative study by Myers, Macintosh, and Goin-Kochel (2009), the interview process with this group of parents yielded dichotomous responses: rich experiences and painful experiences. For all the research groupings (e.g., S1 and P1; S2 and P2; e.g.) the parent(s) had a great deal more to share about their experience for each of the questions than their child had. Similar to Bayat's (2007) findings, despite the extraordinary challenges faced by families of children with ASD, the families in this study somehow showed evidence of resilience. Benson (2010) suggested that, when presented with challenges of having a child with ASD, an avoidant coping method was likely to promote higher levels of stress, particularly in the mother. Positive coping strategies tend to promote a greater sense of well-being, and a greater sense of acceptance of her child. As the parents were interviewed for this research, evidence of positive coping strategies were evident.

Parents: Identified Theme #1

Four of the five parents interviewed stated that having an ASD negatively affected their child's ability to learn, and challenges with the social aspect of learning were cited by all four parents as the primary cause. As documented by many articles, people with ASD have significant challenges in social interaction and communication, and may also have unusual ways of learning and handling information (CDC, 2006). P1 indicated that S1's anxiety about socialization got so severe at times that he refused to participate in the next class or even go to school the following day. Later in the interview, P1 shared that the anxiety and depression got so severe that S1 had to be hospitalized. P5's response about social anxiety was analogous to P1's: The social challenges, beginning in middle school, affected her daughter's learning because of just being in school. She was worried about other kids, which made her feel uncomfortable in her classes. P3 said that S3 performed well academically, but had difficulty in learning situations that were social in nature. P3 recalled that S3 didn't want to join others to work on projects, believing he could do better working on his own. P2 mentioned that S2 had difficulty understanding peers' body language, and would become confused in the interactions with his peers. P3 acknowledged that students learn things from each other: social behavior as well as academic information. Her son's lack of interactions with peers, therefore, negatively impacted affected his ability to learn. Numerous research articles (including Bauminger, Shulman, & Agam, 2003; Beteta, 2009; MacLeod & Johnstone, 2007; Ochs, Kremer-Sadlik, Solomon, & Sirota, 2001; and Price, 2010) cited the social challenges negatively impacting persons with ASD ability to function in school and at work. Only P4 viewed the learning characteristics of a his son with ASD in a positive manner, stating that S4 had a well-developed

memory which allowed him to be successful in school. Baron-Cohen (2000), supports P4's belief, postulating that having an ASD constituted a learning difference, not a learning disability. Three of the parents (P2, P3, and P4) indicated that while certain learning accommodations were recommended, and they wished their student had availed themselves of the accommodation, their children were more concerned with the social stigma accommodations would place on them when among their peers. Humphrey and Lewis's (2008) research supports the feelings of the students in that regard.

Parents: Identified Theme #2

All of the parents indicated it was difficult, in varying degrees, for their children to make friends; yet, no formal social skills instruction class was provided to any of the students in this research group. Additionally, parents indicated there was no support in their child's school to assist with participation in social experiences at school. P4 indicated that a teacher in charge of S4's magnet program encouraged his participation in some clubs, but that was the extent of the support. When a primary deficit of students with ASD was social skills, and social skills affected a student's success in an academic setting, social skills instruction was of paramount importance. P3 stated specifically that she wished there had been a social skills class for S3. Webb, Miller, Pierce, Strawser, and Jones (2004) found that even a time-limited social skills program can make significant gains in student performance of targeted social skills.

Parents: Identified Theme #3

Establishing communication and maintaining a relationship between the school and home was a theme unique to the parent group. Sub-themes of communication and parental involvement were encompassed by this theme. Sansosti, Powell-Smith, and Cowant (2010) stated that “parental involvement may be one of the most critical elements associated with successful outcomes for children with HFA/AS” (p. 35). All parents in this study indicated that they were involved in all IEP and Transition meetings at school, and all found the meetings to be beneficial. P1 mentioned the best part of the IEP process was the opportunity to have discussion time with the professionals involved in her son’s education. P1 had previously voiced frustration that once her son left elementary school there was little communication with the home. Middle school and high school did not attempt direct contact with the family, as the elementary school had, and S1 did not communicate well with mom. So through P1’s involvement in the meetings, her concern about poor communication with S1’s teachers was, at least temporarily, assuaged.

Woodgate, Ateah, and Secco (2008) determined that it was important for parents of children with ASD to educate others: professionals and society in general. P5 exemplified this best when she spoke of S5’s Kindergarten teacher. P5 told the teacher that one can’t always assume S5 knows the rules that the other children know; rules, such as walking in line to the cafeteria, had to be explicitly stated, step by step. Once S5 knew the rule, she would consistently follow it. This kind of communication and involvement with school personnel was essential for S5’s academic and social success in school. P3 shared a similar experience. Her son thought he had caused a power failure in school when he touched something. S3 was extremely bothered by this event, so the teacher called P3. After P3 spoke with her son and explained the situation, S3

calmed down. P3 concluded the conveyance of the story by stating that communication with teachers was important.

P2 mentioned the ability of teachers and parents to communicate through e-mail was very helpful; however, that ability was in its infancy when S2 was in high school. P2 recalled communicating with professionals at S2's IEP meetings, but commented cynically about the recommendations made at the meetings. P2 stated that the recommendations were very good, but they were never fully implemented. Holding schools accountable and supporting schools' efforts to provide appropriate education was a critical role for parents. Sansosti, Powell-Smith, and Cowan (2010) stated that parents should be actively engaged throughout their child's assessment and intervention process, to realize the greatest possible success for their child.

Parents: Identified Theme #4

Three of the parents declared that high school did not prepare their child adequately for the college experience. Three parents indicated that high school and college are very different experiences, and the transition from one experience to the other was a challenge. These statements suggested a theme of preparation for post-secondary experiences. VanBergeikl, Klin, and Volkmar (2008) suggest that careful planning of transition activities is critical for the academic and social success of students with ASD in college settings. VanBergeikl, Klin, and Volkmar strategies that would be helpful to students on the higher end of the autism spectrum. Modifications in the classroom, evaluation and testing of social and academic functioning, and counseling supports are all important components identified by VanBergeikl, Klin, and Volkmar for the success. P1 believed that her son was college-bound, and was unhappy that counselors

with Vocational Rehabilitation seemed more interested in introducing her son to a trade education program. P1 mentioned that the large-group orientation for the community college made her son feel very uncomfortable, but the office supporting students with disabilities was very helpful. P2 shared that their son knew, academically, what to expect in college, but the experience of going away to college was overwhelming for him. P2 said they wished they had done something more to prepare their son for the experience, but they were looking for answers to questions they, themselves, didn't fully understand. P4 wished there had been courses in high school that were similar to course given in college. That would have prepared their son for what to expect in college. It takes time for S4, and others with ASD, to adapt to new situations.

Parents: Discussion of the Findings

As with the graduated student sample, the parent sample intertwined statements related to social challenges for their child throughout their interviews. The researcher learned from responses to interview questions that as difficult as it was for the graduated students to face hardships in the social aspects of school, it was even more difficult for their parents to watch their children go through these difficulties. Every parent wished their child had been more social, but more so, they wanted their children to be happy. All of the parents felt that more could have been done to help their children both socially and academically. P1 ultimately found acceptance in her son's isolation from others, but it was a long, difficult process for her and others in the family. P1 does not push S1 to take part in large group activities in order to avoid another emotional melt-down. P1 acknowledged that even large classrooms would cause a problem for her son. P2 wished for more social experiences for their son, but recognized that he

did have acquaintances with people of similar interests. P3 encouraged her son to participate in social experiences, and he did so out of respect to his mother, not out of desire to participate. P4 wished for more communication with the school, so they would know more about the experiences of their son. P5 knew how bright her daughter was, and wanted as normalized a setting as possible for her. P5 insisted on her daughter's participation in mainstream class settings, but recognized the difficulty her daughter had in being accepted by others in the classes due to her behavioral differences and social naiveté. All the parents expressed frustration at the way their children were treated by others, particularly peers, in the school environment. The feelings of these parents are similar to those in research by Billinton (2006), Billington, McNally, and McNally (2000), and Welton, Vakil, and Carasea (2004).

The parents knew what areas of strength their children possessed, and also understood their learning challenges their child experienced, associated with having an ASD. The need for structure and organization was presented by all of the parents in various ways. Challenges with executive functioning of people with ASD is well documented in research, including VanBergeijk, Klin, & Volkmar, (2008). The need for executive functioning support, whether organizational strategies, time management, or any other executive functioning challenge, is apparent for students throughout the spectrum of autism.

The parents interviewed in this research expressed the need for coordinated social support for their children. Simpson, de Boer-Ott, and Smith-Myles (2003) offered guidelines and a model of support for students with ASD in mainstream settings. Providing social support was one of the five major components in these researchers' methodological model of inclusion for students with ASD. Considering the fact that deficits in social skills is a hallmark component of

the diagnostic criteria for ASD, it is confounding that intentional, structured support was not specifically addressed for any of the students in this research. Parents' interview responses conveyed their frustration of this omission.

Finally, parents wished for more preparation for their child's transition to post-secondary experiences. In this research, all students went on to attend college. VanBergeijk, Klin, and Volkmar (2008) noted that the transition to college is a critical transition juncture that must be carefully planned. Receiving colleges need to be aware of the social, organizational, and communicative supports that are necessary for their learners with ASD. Transition activities to ensure the success of students with ASD in post-secondary experiences should be a critical component of the students' high school experience.

Research Question #3

This study's third research question sought commonalities in the interview responses of the graduated students with those of his/her parent(s). The period of development of the graduated students is well-known for being a period of time of conflict between the adolescent and parent as the teen strives for individuation and autonomy. Typically developing adolescents spend increasing amounts of time with peers, and less time with parents (Steinberg & Morris, 2001). What happens to the classic parent-teen conflict for adolescents with an ASD, who have documented fewer peer interactions than their neurotypical peers?

As distinct groups, the graduated students' response commonalities agreed with the parents' response commonalities in 16 of the 20 interview questions. Of the remaining four questions, two could not be compared for agreement or disagreement because there was no

commonality observed in one or both of the groups. For example, when asked whether there was anything more to say about the educational experience, three graduated students related some type of dissatisfaction about their educational experience, but the parent group had no commonality of response. Each parent had something very different to share; therefore, no comparison of agreement or disagreement could be made. Responses to two questions between the graduated student group and parent group were dissimilar, but did not contradict each other. When asked about a learning experience which was vividly recalled, three graduated students stated they could not recollect a specific learning experience, while four of the parents recollected a positive learning experience. This indicted disagreement in response, but not a contradiction. When asked whether the school social experience was mostly positive or mostly negative, two of the graduated students said that it was “neutral,” neither positive nor negative. Two of the parents said that their children’s experience was negative. Given the richness of responses from the parents, they likely recalled in greater detail some of the difficulties their children experienced. Woodgate, Ateah, and Secco (2008) described a theme of “vigilant parenting” in which the parents became completely focused on every aspect of their children’s (with ASD) world. As such, parents would have greater recollection of their children’s experiences.

Three graduated students mentioned challenges with physical activities. The statements they made included having motor-clumsiness, not being able to kick a ball, being picked-on and picked last in physical education (P.E.), and feeling humiliated and embarrassed in P.E. Motor-clumsiness was documented in research by Thede and Coolidge (2007). Motor-clumsiness was fodder for students with ASD’s feelings of social inadequacy. None of the parents expressed

awareness or concern regarding physical and motor-coordination difficulties impacting their child's social experiences.

Similarities in mood and tone were noted when explicating meaning from the responses of each graduated student and comparing it to their parents responses. Without a doubt, S1's experience throughout school was negative, and his mother's recollection of most of the events reflected the same feelings as her son's. Frea (2010) noted many of the feelings presented throughout S1's and P1's interviews: anger, sadness, desire to be left alone, depression. Some glimmer of hope came through in P1's response that a teacher encouraged S1's talent for writing; however, later P1's mood became more like her son's as she concluded the interview by saying that she honestly thought the school did the best they could with the information they had.

S4 and P4's responses were similar to each others in that they were much more positive in tone. Their responses were most frequently dissimilar to the responses of the others in their respective groups. For example, S4 and P4 indicated that having an ASD did not affect P4's ability to learn. While P4's responses indicated they were vigilant about S4's social experiences, they appeared determined not to let ASD affect their child in a negative way. S4 indicated that he had friends, yet P4 said that it was difficult for S4 to make friends. This dichotomy of responses related to Ochs, Kremer-Sadlik, Solomon, and Sirota's (2001) research, which suggested that students with ASD may, at times, be oblivious to social rejection.

Both S3 and P3 talked about encouragement: P3 ended the interview by stating that her son needed encouragement to participate in social activities all the time, and the most important thing for her to give him was encouragement. S3 concluded his interview by stating that his parents always encouraged him, and encouragement is what everybody needs so that they have

the motivation to make progress. In their qualitative research on raising a child with ASD, Myers, Mackintosh, and Goin-Kochel (2009) noted positive themes in the face of adversity, analogous to the statements expressed by S3 and P3.

Similarities in responses with S5 and P5 gave a feeling of being able to rise above the challenges of having an ASD. P5 believed her advocacy efforts for S5 to be educated in mainstream settings when school personnel insisted on special education classrooms was rewarded by S5's graduation from high school and now college. S5's graduation was a source of pride, as well as relief, for P5. P5 indicated her presence in the school settings, and her availability to inform and instruct teachers about what S5 needs was instrumental in S5's success. P5 made sure appropriate accommodations were in place throughout S5's school career, as well. As P5 had pride in S5's accomplishments, S5 had pride in not being in special education classes. Aware of her mother's efforts, S5 participated in activities because P5 suggested it. P5 and S5 both mentioned how important a "go-to" teacher was to each of them. S5 used this identified teacher to help her in times of social challenges in school. P5 used the teacher as a liaison between school staff and home. This teacher was able to help S5 or P5 with difficulties with students or other staff members before they became bigger problems. Not to dismiss the challenges having an ASD had for S5, P5 acknowledged that there was still a lot of residual pain from the effects of the social experiences S5 endured. Evidence of S5's residual pain appeared when three times during the interview she asked not to be judged her negatively. Research by Soderstrom, Rastam, and Gillberg (2002) noted anxiety and coping difficulties in persons with Asperger's, which is supported by S5's statements.

S2's and P2's interview responses suggested that S2's positive social experiences centered on his artistic ability, and the friendships S2 established and maintained were through their mutual interest in art. The greatest similarity in responses between S2 and P2 were the subsidiary questions for Guide Question 2. Both S2 and P2 acknowledged S2's limited exposure to social experiences. P2 stated that he wished there had been more social experiences; however, S2 seemed satisfied with his connections to others who were interested in art and didn't care to participate in anything else. S2's and P2's observations about S2's friendship development is supported by research by Bauminger and Shulman (2003) who suggested that children with ASD rarely develop friendships spontaneously, but rather through involvement in shared interests and activities.

Implications for Educational Policy and Practice

Based upon the interview responses in this research, suggestions are made for educational policy and practice for students with ASD who are following a standard diploma track in high school. These suggestions serve as the conclusions reached in this study. Due to the overlap of learning experiences and social experiences, suggestions are presented in one group. The suggestions stem from greater understanding of the lived experiences of the research participants.

- Learning accommodations should be implemented with sensitivity and with awareness that most students with ASD do not wish to appear different from their peers.
- Teachers must be well-informed about the nature and needs of students with ASD, while also recognizing that every student with ASD has unique qualities.

- Hand-selection of teachers for the student who has ASD may be necessary. Teachers who are caring, supportive, and who also have a sense of humor are recognized as most effective with this group of students with ASD. Consideration of the unique nature and needs of the student with ASD should be considered when selecting his/her teachers.
- Direct communication between school and home is essential, especially in light of the concern that students with ASD may not share information with their parents.
- School personnel who have specialized training and knowledge of ASD should be identified to act as a liaison between home and school. Such personnel should be available to assist teachers when necessary to avoid a more severe problem due to social or learning challenges.
- Explicit social skills instruction is critical to maximize the possibility of social success of students with ASD.
- Planned, deliberate assistance with school social activities is necessary for students with ASD to participate in school-related experiences.
- Education about ASD and sensitivity training should be provided to peers of students with ASD to ease their acceptance in the mainstream setting.
- Peer mentors and role models should be established for students with ASD so there is an opportunity to learn pro-social skills in as naturalized a setting as possible.
- Alternative methods for earning required credit in physical education must be explored to reduce the negative impact of poor physical skills on social acceptance and self-esteem for the students with ASD. Physical education through Virtual School is a possible alternative.

- Engagement of the parents and the students with ASD in the educational decisions is imperative.
- Students with ASD should be afforded advanced exposure to new educational settings to facilitate the ease of transition.

While some of the suggestions are mandated by federal education law, their practice may not be implemented faithfully. Education professionals working with students with ASD must advocate on behalf of their students and parents to ensure the laws are being met with due diligence. Through faithful practice of educational mandates, adhering to research-based practices, and working with parents as partners in the process, greater academic and social success for students with ASD may be achieved.

Recommendations for Future Research

With greater understanding of the research participants' lived experiences, and with greater awareness of the research process itself, the following recommendations for future research are made.

- When establishing interview questions for future inquiry, assemble an expert focus group to meet face-to-face to develop the research questions. Having dialog among the expert group members would provide added value to this most critical aspect of the research.
- Limit the interview questions to a smaller aspect of challenges associated with ASD, and interview more subjects. For example, limit questions to students' school social experiences, and ask questions from a larger sample of students with ASD.

- Compare responses of students and parents on a narrow topic, and, as in the previous suggestion, use a larger sample to establish strength of implications.
- Interview students with ASD about their school social experience, and compare their answers to the answers of a non-ASD peer group matched for age, sex, and grade level.
- Determine whether there is a qualitative difference in the responses between the mothers and the fathers of children with ASD.
- Describe social and educational interventions and supports that are effective for students with who are on the higher end of the ASD spectrum, and their families.
- Research educational policy and practice that augments social, emotional, and academic success of students with ASD

As more is learned about this perplexing, multi-faceted condition of ASD, greater opportunities will be available for additional research not yet realized. Listening to the words of those with an ASD and their families is an excellent first step.

APPENDIX A
INSTITUTIONAL REVIEW BOARD APPROVAL FROM
UNIVERSITY OF CENTRAL FLORIDA



University of Central Florida Institutional Review Board
 Office of Research & Commercialization
 12201 Research Parkway, Suite 501
 Orlando, Florida 32826-3246
 Telephone: 407-823-2901 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

Approval of Exempt Human Research

From: **UCF Institutional Review Board #1
 FWA00000351, IRB00001138**
 To: **Karen F. Uhle**
 Date: **September 30, 2010**

Dear Researcher:

On 9/30/2010, the IRB approved the following activity as human participant research that is exempt from regulation:

Type of Review: Exempt Determination
 Project Title: Graduated Students with High-Functioning Autism/Asperger Syndrome and Their Parents: Lived Experiences in Public High School
 Investigator: Karen F. Uhle
 IRB Number: SBE-10-07138
 Funding Agency:
 Grant Title:
 Research ID: SBE-10-07138

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the Investigator Manual.

On behalf of Joseph Bielitzki, DVM, UCF IRB Chair, this letter is signed by:

Signature applied by Joanne Muratori on 09/30/2010 02:43:41 PM EDT

IRB Coordinator

APPENDIX B
RESEARCH APPROVAL FROM XXX COUNTY PUBLIC SCHOOLS

Superintendent of Schools
Alberto M. Carvalho

Office of Program Evaluation
Jerome L. Lavitt

County School Board
Dr. Solomon C. Stinson, Chair
Perla Tabares Hartman, Vice Chair
Agustin J. Barrera
Renior Diaz de la Portilla
Dr. Lawrence S. Feldman
Dr. Wilbert "Tee" Holloway
Dr. Martin Stewart Karp
Ana Rivas Logan
Dr. Marta Pérez

EXPEDITED - APPROVAL

October 26, 2010

Mrs. Karen Uhle
8101 S.W. 151st Street

Dear Mrs. Uhle:

I am pleased to inform you that the Research Review Committee (RRC) of the County Public Schools (CPS) has granted you approval for your request to conduct the study: "Graduated Students with High Functioning Autism and Their Parents: Lived Experiences in Public High School" in order to fulfill the requirements of your Dissertation at the University of Central Florida.

The approval is granted with the following conditions:

1. Participation of the schools targeted in this study is at the discretion of each principal. Please note that even with the approval of the RRC, it is still the responsibility of the Principal as the gatekeeper of the school to decide whether to participate or not. As stated in the Board rule, *"... the principal of the individual school has the privilege of deciding if RRC-approved research will be conducted within his/her school."* A copy of this approval letter must be presented to each principal.
2. The participation of all subjects (such as students, faculty, or staff) is **voluntary**.
3. The anonymity and/or confidentiality of all subjects must be assured.
4. Parent permission forms must be secured for all participating students prior to the beginning of the study.
5. The study will involve approximately 5 students (who graduated from CPS) and their Parents.
6. Disruption of the school's routine by the data collection activities of the study must be kept at a minimum. Data collection activities must not interfere with the district's testing schedule.
7. ALL research activities must be conducted with the knowledge and approval of the Principal. All efforts should be made to minimize any negative impact on the learning environment.
8. The interviews of the graduating students and their parents, must be conducted outside the school sites.

Office of Program Evaluation • 1500 Biscayne Boulevard • Suite 224 •
305-995-7529 • 305-995-2691(FAX) • www.schools.net

It should be emphasized that the approval of the Research Review Committee does not constitute an endorsement of the study. It is simply a permission to request the voluntary cooperation in the study of individuals associated with CPS.

The archival data that you are requesting may not be available or may not be easily accessible. To that end, you may incur the cost to retrieve the archival data. Please contact Ms. Gisela Feild, Administrative Director at 305-995-2943 to discuss your data request and determine cost and timelines.

It is your responsibility to ensure that appropriate procedures are followed in requesting an individual's cooperation, and that all aspects of the study are conducted in a professional manner. With regard to the latter, make certain that all documents and instruments distributed within CPS as a part of the study are carefully edited.

The approval number for your study is **1685**. This number should be used in all communications to clearly identify the study as approved by the Research Review Committee. The approval expires on **June 30, 2011**. During the approval period, the study must adhere to the design, procedures and instruments which were submitted to the Research Review Committee.

Finally, as indicated in your application, please submit to the RRC an abstract of the research findings by **July, 2011**.

If there are any changes in the study as it relates to CPS, the RRC must be notified in writing. Substantial changes may necessitate resubmission of the request. Failure to notify me of such a change may result in the cancellation of the approval.

If you have any questions, please call me at 305-995-7529. On behalf of the Research Review Committee, I want to wish you every success with your study.

Sincerely,



Tarek Chebbi, Ed. D.
Chairperson
Research Review Committee

TC:bf

APPROVAL NUMBER: **1685**

APPROVAL EXPIRES: **06/30/2011**

Note: The researcher named in this letter of approval will be solely responsible and strictly accountable for any deviation from or failure to follow the research study as approved by the RRC. CPS will NOT be held responsible for any claim and/or damage resulting from conducting this study.

APPENDIX C
INFORMED CONSENT FOR PARTICIPATION IN RESEARCH

Graduated Students with High Functioning Autism and Their Parents: Lived Experiences with the Educational System Informed Consent for an Adult in a Non-Exempt Research Study

Principal Investigator(s): Karen F. Uhle, Doctoral Student, University of Central Florida

Faculty Supervisor: Suzanne Martin, PhD

Investigational Site(s): XXX County Public School System

Introduction: Researchers at the University of Central Florida (UCF) study many topics. To do this we need the help of people who agree to take part in a research study. You are being invited to take part in a research study that will include about ten people in XXX-Dade County. You have been asked to take part in this research study because you are a graduated student with autism spectrum disorder, or the parent of a graduated student with autism spectrum disorder. You must be 18 years of age or older to be included in the research study.

The person doing this research is Karen F. Uhle, participant in the National Urban Special Education Leadership grant through University of Central Florida. Because the researcher is a graduate student, she is being guided by Dr. Suzanne Martin, a UCF faculty supervisor in the College of Education.

What you should know about a research study:

- Someone will explain this research study to you.
- A research study is something you volunteer for.
- Whether or not you take part is up to you.
- You should take part in this study only because you want to.
- You can choose not to take part in the research study.
- You can agree to take part now and later change your mind.
- Whatever you decide it will not be held against you.
- Feel free to ask all the questions you want before you decide.

Purpose of the research study: The purpose of this study is to contribute to the body of literature that describes the unique academic, social, and personal experiences of students with ASD, and his/her parents. This research will attempt to identify common themes of the students' and parents' lived experiences with the public school system so that programmatic adjustments

may be implemented which could better address the needs of students with ASD. Parents' lived experiences also may suggest approaches educators can use to instill a positive working relationship with the parents of the students with ASD. An analysis of responses from the students and parents may suggest areas of support to provide desired outcomes for both the students and their families. With a multiple-participant phenomenological research design, the strength of any inference made increases when factors recur with more than one participant.

What you will be asked to do in the study: Research participants will be asked to respond to questions which ask about the participant's experience in this large urban school district. All research participants will be asked the same questions. Each interview is anticipated to take no longer than an hour of time.

- Subjects will be interviewed by the principal investigator
- All interviews will be audio-recorded
- Graduated student and his/her parent(s) must agree to participate
- Graduated students and parents must not discuss their responses to interview questions prior to the interview

Location: The researcher will meet the participant at an agreed upon public library which has a private room that may be used for the interview.

Time required: We expect that you will be in this research study for a single one-hour interview session.

Audio taping: You will be audio taped during this study. If you do not want to be audio taped, you will not be able to be in the study. Discuss this with the researcher or a research team member. If you are audio taped, the tape will be kept in a locked, safe place. The tape will be erased or destroyed when the transcription of the audiotape has been verified by the researcher.

Risks: While not anticipated, participants may have some discomfort if recalling schools experiences that were unpleasant. Otherwise, there are no reasonably foreseeable risks or discomforts involved in taking part in this study.

Benefits: There are no expected benefits to you for taking part in this study. However, possible benefits for future students include improved programs and procedures for students with high functioning autism and their families.

Compensation or payment: There is no compensation or other payment to you for taking part in this study.

Confidentiality: We will limit your personal data collected in this study to people who have a need to review this information. We cannot promise complete secrecy. Organizations that may inspect and copy your information include the IRB and other representatives of UCF. Research

participants will be coded, and the study will be written with the participant's code rather than any other identification.

Study contact for questions about the study or to report a problem: If you have questions, concerns, or complaints, or think the research has hurt you, talk to Dr. Suzanne Martin, Faculty Supervisor, National Urban Special Education Leadership Initiative Grant, College of Education at (407) 823-4260 or by email at Martin@mail.ucf.edu

IRB contact about your rights in the study or to report a complaint: Research at the University of Central Florida involving human participants is carried out under the oversight of the Institutional Review Board (UCF IRB). This research has been reviewed and approved by the IRB. For information about the rights of people who take part in research, please contact: Institutional Review Board, University of Central Florida, Office of Research & Commercialization, 12201 Research Parkway, Suite 501, Orlando, FL 32826-3246 or by telephone at (407) 823-2901. You may also talk to them for any of the following:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You want to get information or provide input about this research.

Your signature below indicates your permission to take part in this research.

**DO NOT SIGN THIS FORM AFTER THE IRB EXPIRATION DATE
BELOW**

Name of participant

Signature of participant

Date

Signature of person obtaining consent

Date

Printed name of person obtaining consent

APPENDIX D
GUIDE AND SUBSIDIARY QUESTIONS: STUDENT INTERVIEW

Guide and Subsidiary Questions: Student Interview

Introduction

The purpose of this study is to determine your educational and social experience in the urban public school system. Based upon your experiences as a graduated student with an autism spectrum disorder, you are in a pivotal position to provide feedback and insight relative to providing educational and social support to students with autism in the public school setting.

The interview has been designed for you to respond to three guide questions, with seven to eight subsidiary questions for each guide question. Your responses will be combined with responses of four other graduated students with autism, as well as your parents and the other students' parents participating in this study. Nothing you say will be identified with you personally. As we go through the interview, please feel free to stop and ask any questions you may have or for clarification. If there is a question you do not wish to respond to, please say so.

Do you have any questions before we begin the interview?

Guide Question #S1: What was your educational experience as a student in the urban public school system?

Subsidiary Questions:

- S1.1 Did having an autism spectrum disorder affect your ability to learn? If so, how?
- S1.2 Describe the classes or learning environments in which you felt successful.
- S1.3 Describe the classes or learning environments that were the most challenging for you.
- S1.4 What help – if any – did your parents provide with home-learning assignments?
- S1.5 What learning accommodations did you believe to be the most helpful?
- S1.6 During your school experience you may have worked with many different teachers.

Without naming any specific teacher or teachers, tell me about the characteristics of those teachers (e.g., sense of humor, classroom management skills, instructional methods) you feel were most effective in helping you achieve your academic goals.

- S1.7 You have had many academic experiences throughout your years in school. Please tell me about a learning experience that you vividly recall.
- S1.8 Is there anything else you would like to share about your educational experiences in school?

Guide Question #S2: What was your social experience as a student in the urban public school system?

Subsidiary Questions:

- S2.1 Did you participate in a social skills class? If so, please describe your experience and any changes you have made as a result.

- S2.2 Did you participate in any clubs and/or after school activities, including senior events (e.g., Grad Night, Senior Prom, graduation)?
- S2.2.1 If you didn't participate ...
- S2.2.1.a Did you want to participate?
- S2.2.1.b Who or what kept you from participating?
- S2.2.2 If you did participate...
- S2.2.2.a In which activities did you participate?
- S2.2.2.b Describe your experience as you participated in these activities.
- S2.3 What help did school personnel provide, if any, for your participation in social activities?
- S2.3.1 Describe any help that you received.
- S2.3.2 Was this help effective? Why or why not?
- S2.4 Tell me about the friends you had in school.
- S2.4.1 Was it easy or difficult for you to make friends? Please explain.
- S2.4.2 How would you classify most of your friends: students with ASD or neurotypicals (without ASD)?
- S2.5 Would you characterize your social experiences in school as mostly positive or mostly negative? Please explain your response.
- S2.6 Is there a social experience you had in school that you vividly recall? If so, please describe what you recall.
- S2.7 Is there anything else you would like to say about your social experience in school?

Guide Question #S3: What do you remember about your involvement, and your parent(s)' involvement, in your school experience?

Subsidiary Questions:

- S3.1 Did you participate in your individual education plan (IEP) meetings?
 - S3.1.1 If you participated please describe your experience in these meetings.
 - S3.1.2 Did your parent(s) participate in your IEP meetings?
- S3.2 Was there a time your parent(s) requested an academic experience and/or learning accommodation in which you were not in agreement?
 - S3.2.1 If you didn't agree...
 - S3.2.1.a Please describe the situation with which you did not agree.
 - S3.2.1.b What did you want instead?
 - S3.2.1.c From your perspective, whose request received support from school personnel?
- S3.3 Do remember a time when your parent(s) wanted something for your school social experience in which you were not in agreement?
 - S3.3.1 If you didn't agree...
 - S3.3.1.a Please describe the situation with which you did not agree
 - S3.3.1.b What did you want instead?
 - S3.3.1.c From your perspective, whose request received support from school personnel?
- S3.4 Did you participate in meetings for transition into post-secondary school educational or vocational opportunities?

- S3.4.1 If you participated, please describe your experience in these meetings.
- S3.4.2 Did your parents participate in your transition meetings?
- S3.4.3 How well do you feel your school experience prepared you for post-secondary opportunities such as additional education or employment?
- S3.5 Is there anything else you would like to tell me about your parent(s) involvement in your academic and social experiences in public school?

APPENDIX E
GUIDE AND SUBSIDIARY QUESTIONS: PARENT INTERVIEW

Guide and Subsidiary Questions: Parent Interview

Introduction

The purpose of this study is to determine your experience with the urban public school system in the educational and social process for your child with an autism spectrum disorder. Based upon your experiences as the parent of a graduated student with an autism spectrum disorder, you are in a pivotal position to provide feedback and insight relative to providing educational and social support to students with autism, and their parents, in the public school setting.

The interview has been designed for you to respond to three guide questions, with seven to eight subsidiary questions for each guide question. Your responses will be combined with responses of four other parents of graduated students with autism, as well as with the students participating in the study. Nothing you say will be identified with you personally. As we go through the interview, please feel free to stop and ask any questions you may have or for clarification. If there is a question you do not wish to respond to, please say so.

Do you have any questions before we begin the interview?

Guide Question #P1: What was your experience as the parent of a student with an autism spectrum disorder in an urban public school system in meeting your child's academic needs?

Subsidiary Questions:

P1.1 Did having an autism spectrum disorder affect your child's ability to learn? If so, how?

P1.2 Describe the classes or learning environments where you believe your child was most successful.

P1.3 Describe the classes or learning environments that were the most challenging for your child.

P1.4 What help – if any – did you provide to your child for home-learning assignments?

P1.5 What learning accommodations do you believe were most helpful for your child?

P1.6 During your child's school experience, s/he may have had many different learning experiences. Without naming any specific teacher or teachers, which teacher characteristics (e.g., sense of humor, classroom management skills, instructional methods) do you feel were most effective in helping your child achieve his/her academic goals?

P1.7 Your child has had many academic experiences throughout his/her years in school. Please tell me about a learning experience that you vividly recall.

P1.8 Is there anything else you would like to share about your child's educational experience in school?

Guide Question #P2: What were your child's social experiences as a student with an autism spectrum disorder in the urban public school system?

Subsidiary Questions:

- P2.1 Did your child participate in a social skills class? If so, please describe this experience and any changes in your child you may have observed as a result.
- P2.2 Did your child participate in any clubs and/or after school activities, including senior events (e.g., Grad Night, Senior Prom, graduation)?
- P2.2.1 If your child didn't participate ...
- P2.2.1.a Did your child want to participate?
- P2.2.1.b Who or what kept your child from participating?
- P2.2.2 If your child did participate...
- P2.2.2.a In which activities did s/he participate?
- P2.2.2.b What feelings and/or thoughts did you have as your child participated in these activities?
- P2.3 What help did school personnel provide, if any, for your child's participation in social activities?
- P2.3.1 Describe any help that your child received.
- P2.3.2 Was this help effective? Why or why not?
- P2.4 Tell me about the friends your child had in school.
- P2.4.1 Was it easy or difficult for your child to make friends? Please explain.
- P2.4.2 How would you classify most of your child's friends: students with ASD or neurotypicals (without ASD)?
- P2.5 Would you characterize your child's social experiences in school as mostly positive or mostly negative? Please explain your response.

- P2.6 Is there a social experience your child had in school that you vividly recall? If so, please describe what you recall.
- P2.7 Is there anything else you would like to say about your child's social experiences in school?

Guide Question #P3: What do you remember about your involvement and your child's involvement in his/her school experience?

Subsidiary Questions:

- P3.1 Did you participate in your child's individual education plan (IEP) meetings?
- P3.1.1 If you participated please describe your experience in these meetings.
- P3.1.2 Did your child participate in his/her IEP meetings?
- P3.2 Was there a time when you requested an academic experience and/or learning accommodation in which your child did not agree?
- P3.2.1 If you didn't agree...
- P3.2.1.a Please describe the situation with which you did not agree.
- P3.2.1.b What did your child want instead?
- P3.2.1.c From your perspective, whose request received support from school personnel?
- P3.3 Do you remember a time when you wanted something for your child's school social experience in which your child did not agree?
- P3.3.1 If you didn't agree...
- P3.3.1.a Please describe the situation with which you did not agree.

P3.3.1.b What did your child want instead?

P3.3.1.c From your perspective, whose request received support from school personnel?

P3.4 Did you participate in meetings for your child's transition into post-secondary school educational or vocational opportunities?

P3.4.1 If you participated, please describe your experience in these meetings.

P3.4.2 Did your child participate in your transition meetings?

P3.4.3 How well do you feel your child's school experience prepared him/her for post secondary opportunities such as additional education or employment?

P3.5 Is there anything else you would like to tell me about your involvement in your child's academic and social experiences in public school?

APPENDIX F
EXPERT FOCUS GROUP LETTER AND SCORING RUBRIC FOR GUIDE
AND SUBSIDIARY INTERVIEW QUESTIONS

Date _____

Dear Special Education Professional:

As part of my doctoral studies, I am conducting a qualitative research study on the lived experiences of students with high functioning autism spectrum disorders and their parents in the process of attaining a standard high school diploma from a large urban public school system.

Your status as a special educator in this school district, as well as your National Board Certification status in the area of Exceptional Needs Specialist, makes you uniquely qualified to offer guidance to my research.

I have developed a list of guide questions and subsidiary questions which, I believe, will answer the research questions of:

- 1) What are the lived experiences of graduated students with ASD in this urban public school system?
- 2) What are the lived experiences of the parents of the graduated students with ASD in this urban public school system?
- 3) Are there common themes between the graduated students' lived experiences and the parents' lived experiences?

On the attached form, please evaluate each of the guide questions and subsidiary questions I have developed in terms of the question's ability to identify subject's (students and parents) lived academic, social, and participatory experience in school.

Any comments or suggestions you have are greatly appreciated. Kindly return your evaluation form in the enclosed self-addressed stamped envelope.

Please accept, as a token of my appreciation for your time, this Restaurant.com gift certificate.

Most Sincerely,

Karen F. Uhle, NBCT
Doctoral Candidate, University of Central Florida
National Urban Special Education Leadership Initiative

Question Rating Guidelines

Your careful review and recommendation of all guide and subsidiary questions are critical to this research.

You are asked to evaluate each guide and subsidiary question that will be asked of the research subjects. Questions may be rated as *Acceptable* or *Unacceptable*; your comments on any or all of the questions are welcome.

To rate a Guide or Subsidiary question as *Acceptable*, please keep the following in mind:

Is the language in the question appropriate for the subject (e.g., refrain from use of jargon)?

Is the length of the question appropriate for ease of understanding?

Does the question relate to a topic of concern for students with autism spectrum disorders?

If you rate a Guide or Subsidiary question *Unacceptable*, please provide the rationale for this rating, and any suggestions you have for revision.

Student Interview Questions

Rating scale:

A = Acceptable

U = Unacceptable

Question	Rating	Comment
<i>Guide Question #S1: What was your educational experience as a student in the urban public schools?</i>	5/5 = A	
S1.1 Did having an autism spectrum disorder affect your ability to learn? If so, how?	5/5= A	
S1.2 Describe the classes or learning environments in which you felt successful.	4/5 = A	Open-ended
S1.3 Describe the classes or learning environments that were the most challenging for you.	4/5 = A	Open-ended; difficult to measure
S1.4 What help – if any – did your parents provide with home-learning assignments?	5/5= A	Should you take out “if any”?
S1.5 What learning accommodations did you believe to be the most helpful?	5/5= A	
S1.6 During your school experience you may have worked with many different teachers. Without naming any specific teacher or teachers, tell me about the characteristics of those teachers (e.g., sense of humor, classroom management skills, instructional methods) you feel were most effective in helping you achieve your academic goals.	4/5 = A	Too qualitative, touchy-feely type question. This seems too lengthy. Most important with previous questions asked. Good- you give examples of characteristics.
S1.7 You have had many academic experiences throughout your years in school. Please tell me about a learning experience that you vividly recall.	5/5 = A	May have to prompt, give examples.
S1.8 Is there anything else you would like to share about your educational experiences in school?	4/5 = A	

<i>Guide Question #S2: What was your social experience as a student in an urban public school?</i>	5/5 = A	
S2.1 Did you participate in a social skills class? If so, please describe your experience and any changes you have made as a result.	5/5= A	Rather than “any changes...” consider “What did you learn that was helpful?”
S2.2 Did you participate in any clubs and/or after school activities, including senior events (e.g., Grad Night, Senior Prom, graduation)?	5/5= A	
S2.2.1 If you didn’t participate ... S2.2.1.a Did you want to participate? S2.2.1.b Who or what kept you from participating?	5/5= A	2.2.1 and 2.2.2- I like that you have branched your questions based on the students’ responses.
S2.2.2 If you did participate... S2.2.2.a In which activities did you participate? S2.2.2.b Describe your experience as you participated in these activities.	5/5= A	
S2.3 What help did school personnel provide, if any, for your participation in social activities?	5/5= A	“if any” ? Maybe ask about friends or parent support/help also.
S2.3.1 Describe any help that you received. S2.3.2 Was this help effective? Why or why not?	4/5= A	These are not necessary if the answer to S2.3 is “none”.
S2.4 Tell me about the friends you had in school.	4/5= A	Very open- may answer S2.4.2
S2.4.1 Was it easy or difficult for you to make friends? Please explain.	5/5= A	
S.2.4.2 How would you classify most of your friends: students with ASD or neurotypicals (without ASD)?	5/5= A	Should you use “neurotypicals”? Okay- if they know and use “neurotypicals”

S2.5 Would you characterize your social experiences in school as mostly positive or mostly negative? Please explain your response.	5/5= A	Consider making this S2.1
S2.6 Is there a social experience you had in school that you vividly recall? If so, please describe what you recall.	4/5= A	
S2.7 Is there anything else you would like to say about your social experience in school?	4/5= A	Sort of redundant.

<i>Guide Question #S3: What do you remember about your involvement, and your parent(s)' involvement, in your school experience?</i>	5/5= A	
S3.1 Did you participate in your individual education plan (IEP) meetings?	5/5= A	Excellent!
S3.1.1 If you participated please describe your experience in these meetings.	4/5= A	Maybe indicate to what extent
S3.1.2 Did your parent(s) participate in your IEP meetings?	5/5= A	
S3.2 Was there a time your parent(s) requested an academic experience and/or learning accommodation in which you were not in agreement?	5/5= A	I really like this one. Excellent!
S3.2.1 If you didn't agree... S3.2.1.a Please describe the situation with which you did not agree.	5/5= A	Excellent!
S3.2.1.b What did you want instead?	5/5= A	Excellent!
S3.2.1.c From your perspective, whose request received support from school personnel?	5/5= A	Excellent!
S3.3 Do you remember a time when your parent(s) wanted something for your school social experience in which you were not in agreement?	5/5= A	Again, I like this line of questioning, the students' wishes are often ignored. Excellent!
S3.3.1.b What did you want instead?	5/5= A	Excellent!

Question	Rating	Comment
S3.3.1.c From your perspective, whose request received support from school personnel?	5/5= A	Excellent!

S3.4 Did you participate in meetings for transition into post-secondary school educational or vocational opportunities?	5/5= A	
S3.4.1 If you participated, please describe your experience in these meetings.	4/5= A	
S3.4.2 Did your parents participate in your transition meetings?	5/5= A	
S3.4.3 How well do you feel your schoolexperience prepared you for post-secondary opportunities such as additional education or employment?	4/5= A	
S3.5 Is there anything else you would like to tell me about your parent(s) involvement in your academic and social experiences in public school?	4/5= A	

Parent Interview Questions

Rating scale:

A = Acceptable

U = Unacceptable

Question	Rating	Comment
<i>Guide Question #P1: What was your educational experience as the parent of a student with an autism spectrum disorder in an urban public school system?</i>	5/5= A	
P1.1 Did having an autism spectrum disorder affect your child's ability to learn? If so, how?	4/5= A	
P1.2 Describe the classes or learning environments in which you believe your child was most successful.	5/5= A	
P1.3 Describe the classes or learning environments that were the most challenging for your child.	5/5= A	
P1.4 What help – if any – did you provide to your child with home-learning assignments?	5/5= A	
P1.5 What learning accommodations did you believe to be the most helpful for your child?	5/5= A	
P1.6 During your school experience your child may have worked with many different teachers. Without naming any specific teacher or teachers, tell me about the characteristics of those teachers (e.g., sense of humor, classroom management skills, instructional methods) you feel were most effective in helping your child achieve his/her academic goals.	4/5= A	
P1.7 Your child has had many academic experiences throughout your years in school. Please tell me about a learning experience that you vividly recall.	5/5= A	
P1.8 Is there anything else you would like to share about your child's educational experiences in school?	5/5= A	

<i>Guide Question #P2: What was your child's social experience as a student in an urban public school system?</i>	4/5= A	
P2.1 Did your child participate in a social skills class? If so, please describe your experience and any changes you may have observed as a result.	5/5= A	
P2.2 Did your child participate in any clubs and/or after school activities, including senior events (e.g., Grad Night, Senior Prom, graduation)?	5/5= A	
P2.2.1 If your child didn't participate ... P2.2.1.a Did your child want to participate? P2.2.1.b Who or what kept your child from participating?	5/5= A	
P2.2.2 If your child did participate... P2.2.2.a In which activities did your child participate? P2.2.2.b What feelings and/or thoughts did you have as your child participated in these activities?	5/5= A	
P2.3 What help did school personnel provide your child, if any, for his/her participation in social activities?	4/5= A	
P2.3.1 Describe any help that your child received. P2.3.2 Was this help effective? Why or why not?	4/5= A	
P2.4 Tell me about the friends your child had in school.	4/5= A	Too qualitative
P2.4.1 Was it easy or difficult for your child to make friends? Please explain.	5/5= A	
P2.4.2 How would you classify most of your child's friends: students with ASD or neurotypicals (without ASD)	5/5= A	

Question	Rating	Comment
P2.5 Would you characterize your child's social experiences in school as mostly positive or mostly negative? Please explain your response.	5/5= A	
P2.6 Is there a social experience your child had in school that you vividly recall? If so, please describe what you recall.	5/5= A	
P2.7 Is there anything else you would like to say about your child's social experience in school?	5/5= A	

<i>Guide Question #P3: What do you remember about your involvement, and your child's involvement, in his/her school experience?</i>	5/5= A	
P3.1 Did you participate in your child's individual education plan (IEP) meetings?	5/5= A	
P 3.1.1 If you participated please describe your experience in these meetings.	4/5= A	
P3.1.2 Did your child participate in his/her IEP meetings?	5/5= A	
P3.2 Was there a time you requested an academic experience and/or learning accommodation in which your child did not agree?	5/5= A	It will be interesting to compare parents' perspectives about this with the students' answers.
P3.2.1 If you didn't agree... P3.2.1.a Please describe the situation with which you did not agree.	4/5= A	Shouldn't this be "your child" (instead of "you")? See P3.2 and P3.2.1.b
P3.2.1.b What did your child want instead?	4/5= A	

Question	Rating	Comment
P3.2.1.c From your perspective, whose request received support from school personnel?	4/5= A	Too opinionated
P3.3 Do remember a time when you wanted something for your school social experience in which your child did not agree?	5/5= A	
P.3.3.1 If you didn't agree... P3.3.1.a Please describe the situation with which you did not agree.	4/5= A	Again, "your child" instead of "you", P3.3 and P3.3.1.
P3.3.1.b What did your child want instead?	5/5= A	
P3.3.1.c From your perspective, whose request received support from school personnel?	5/5= A	

Question	Rating	Comment
P3.4 Did you participate in your child's meetings for transition into post-secondary school educational or vocational opportunities?		
S3.4.1 If you participated, please describe your experience in these meetings.		
S3.4.2 Did your child participate in his/her transition meetings?		
S3.4.3 How well do you feel your child's school experience prepared him/her for post-secondary opportunities such as additional education or employment?		
S3.5 Is there anything else you would like to tell me about your involvement in your child's academic and social experiences in public school?		

APPENDIX G
LETTER OF INTRODUCTION AND PARTICIPATION REQUEST TO
POTENTIAL RESEARCH SUBJECTS

Name of (Parent/Student)
(High School) Name
Address
XXX, FL, Zip Code

Date:

Dear (Parent/Student):

I am a doctoral student at the University of Central Florida, Orlando Florida and a participant in the National Urban Special Education Leadership Initiative through the College of Education.

Currently I am working on a dissertation titled: Graduated Students with Autism Spectrum Disorders and Their Parents: Lived Experiences in Pubic High School. This research study will provide educational policy-makers and professionals in our school district the opportunity to better understand the experience of students with high functioning autism spectrum disorders and their parents. As a potential subject of this study, this letter is written to explain how your participation is vital to this research.

The purpose of this letter is to request your participation in this study. You are invited to meet with me for an interview session at which time I would have the opportunity to listen to your views on your experience while receiving special education services in this urban public school system. Upon request, the questions asked in this interview will be made available for your review prior to your commitment to this study. All subjects will have a chance to review the questions at least two days prior to the interview.

Should you agree to participate in this research study, a date and time will be scheduled for our meeting at a location convenient for you. The interview will take no longer than approximately one hour of your time in a given day.

Your consent to be interviewed as part of this research study is completely voluntary. While there are no direct benefits to you, your participation is vital and important to this research study. Not only does your input add to the knowledge base of educational experiences of individuals with autism spectrum disorders and their families, it also provides support and valued information to current, as well as future, educators.

Your name and the name of your school will be coded in the research study. Your agreement to participate gives permission for the interview to be audio taped; however, once the audiotape has been transcribed and verified, you may request to have your portion of the tape destroyed.

To maintain confidentiality, research material and interview notes will be kept securely stored in a locked file cabinet for a minimum of three years. The data will only be available to the researcher and to the dissertation committee.

If you are willing to participate, please complete the enclosed form and return it in the self-addressed, stamped envelop. If you have any questions, I may be contacted directly at

786-271-2876, or via e-mail at karenuhle@att.net. Please note that in order to participate in the study, both student and parent(s) must agree to participate.

Thank you in advance for your consideration and consent to participate in this study.

Sincerely,

Karen Uhle

Doctoral Student, University of Central Florida

APPENDIX H
THREE POINT SCALE COMPARING GRADUATED STUDENT
AND PARENT RESPONSES
FOR RESEARCHER'S USE

Three-Point Scale Comparing Graduated Student and Parent Responses

For Researcher's Use

For each Guide question and Subsidiary questions, evaluate the level of agreement between the student's response and his/her parent's response.

Agree = 2

Disagree = 1

Undecided or Unable to evaluate = 0

*Guide or
Subsidiary Question Score Comment*

S/P Guide Question 1		
S/P 1.1		
S/P 1.2		
S/P 1.3		
S/P 1.4		
S/P 1.5		
S/P 1.6		
S/P 1.7		
S/P 1.8		
S/P Guide Question 2		
S/P 2.1		
S/P 2.2		
S/P 2.2.1		
S/P 2.2.1.a		
S/P 2.2.1.b		
S/P 2.2.2		
S/P 2.2.2.a		

S/P 2.2.2.b		
S/P 2.3		
S/P 2.3.1		
S/P 2.3.2		
S/P 2.4		
S/P 2.4.1		
S/P 2.4.2		
S/P 2.5		
S/P 2.6		
S/P 2.7		
S/P Guide Question 3		
S/P 3.1		
S/P 3.1.1		
S/P 3.1.2		
S/P 3.2		
S/P 3.2.1.a		
S/P 3.2.1.b		
S/P 3.2.1.c		
S/P 3.3		
S/P 3.3.1.a		
S/P 3.3.1.b		
S/P 3.3.1.c		
S/P 3.4		
S/P 3.4.1		
S/P 3.4.2		

S/P 3.4.3		
S/P 3.5		

APPENDIX I
TRANSCRIPTIONS OF GRADUATED STUDENT INTERVIEWS

Guide and Subsidiary Questions are printed in boldface.

Student responses in standard font.

Researcher prompts and clarifications are italicized within parentheses.

Significant field notes are italicized without parentheses.

S1 Interview Responses

Guide Question #S1

Subsidiary Questions: : *What was your educational experience as a student in an urban public school system?*

S1.1 Did having an autism spectrum disorder affect your ability to learn? If so, how?
I'm not entirely sure. I think definitely a post-problem for attention span when things weren't very interesting, or when things were too easy or too hard for my skill level. But specifically I don't know.

S1.2 Describe the classes or learning environments in which you felt successful.

The ones where teachers placed understanding and all that – above 'by the book' stuff.

(Q- understanding?) Academically, emotionally.

S1.3 Describe the classes or learning environments that were the most challenging for you.

That would probably be the ones where I was forced to socialize against my will. Places like P.E., among others, were nothing more than a public embarrassment.

S1.4 What help – if any – did your parents provide with home-learning assignments?

I know my mom helped, I don't remember how exactly. *(Q- did she help academically? organization? Do you remember what kind of help?)*.

Not really.

S1.5 What learning accommodations did you believe to be the most helpful?

(Clarification of 'accommodations')

Probably extended time so I wouldn't be expected to keep pace with non-autistic students.

S1 Transcribed Responses

S1.6 During your school experience you may have worked with many different teachers. Without naming any specific teacher or teachers, tell me about the characteristics of those teachers (e.g., sense of humor, classroom management skills, instructional methods) you feel were most effective in helping you achieve your academic goals.

The more humorous or open-minded teachers were definitely my preference. Even when I didn't do the work, they knew it wasn't necessarily because I was lazy, but because I wasn't interested or it was too easy.

S1.7 You have had many academic experiences throughout your years in school. Please tell me about a learning experience that you vividly recall.

Can you be more specific?

(Something that sticks out in your mind as an experience you remember- very vivid in your brain. It could have been a positive experience or a negative experience.)

S1 appears uneasy—more probing

(sighs-)

More probing- and reminding he has an option not to reply

I think if I do have any memories to apply, which I'm sure I do, they are probably repressed.

S1.8 Is there anything else you would like to share about your educational experiences in school?

I don't believe it was very successful. Partly because of the teachers and the academic programs; partly because the special education was too distinct from the rest of the school programs that

S1 Transcribed Responses

made people targets. Even within the programs, those who were considered ‘better’, or just needed to feel better about themselves targeted others. And eventually it came to be that I partially hated school because of all the people judging.

Guide Question #S2: What was your social experience as a student in XXX-Dade County Public Schools?

S2.1 Did you participate in a social skills class? If so, please describe your experience and any changes you have made as a result.

I was diagnosed far too late to have been lucky enough to get into one.

S2.2 Did you participate in any clubs and/or after school activities, including senior events (e.g., Grad Night, Senior Prom, graduation)?

S2.2.1 If you didn’t participate ...

S2.2.1.a Did you want to participate?

S2.2.1.b Who or what kept you from participating?

No I did not, except for graduation.

(Q- describe your experience as you went through graduation)

It was nerve-wracking and sweaty, and not a very pleasant thing. I just wanted to get it over with and go home.

S1 Transcribed Responses

S2.3 What help did school personnel provide, if any, for your participation in social activities?

Absolutely none.

S2.4 Tell me about the friends you had in school.

S2.4.1 Was it easy or difficult for you to make friends? Please explain.

Very difficult. I believe I knew in theory how to make friends, but in practice it was very intimidating.

S.2.4.2 How would you classify most of your friends: students with ASD or neurotypicals (without ASD)?

Pretty much all of them were neurotypical.

S2.5 Would you characterize your social experiences in school as mostly positive or mostly negative? Please explain your response.

(Snorts) To put it bluntly, mostly negative. The number of humiliations, embarrassments and misunderstandings vastly outweighed the positive experiences.

S2.6 Is there a social experience you had in school that you vividly recall? If so, please describe what you recall.

Many- but I'd like to focus on one during – I think it was Junior year at Palmetto. I was sitting around with a group of friends at lunch. I had taken a habit of sitting with them every once in a while, but very rarely did I speak. This caused one of the group to think there was something seriously wrong with me. At one point she seemed convinced that I would be- or had been- a serial killer. Not knowing how to express my response, I kind of

S1 Transcribed Responses

smiled weakly. I imagine this didn't exactly help her perception, but I wish she didn't have to make that perception in the first place.

S2.7 Is there anything else you would like to say about your social experience in school?

That it was hellish, and I never want to go through that again.

Guide Question #S3: What do you remember about your involvement, and your parent(s) involvement, in your school experience?

S3.1 Did you participate in your individual education plan (IEP) meetings?

Yes, but I'm not sure at which point I began to be included in them.

S3.1.1 If you participated please describe your experience in these meetings.

Fairly neutral

S3.1.2 Did your parent(s) participate in your IEP meetings?

Yes

S3.2 Was there a time your parent(s) requested an academic experience and/or learning accommodation in which you were not in agreement?

To my knowledge nothing was really requested.

S3.3 Do remember a time when your parent(s) wanted something for your school social experience in which you were not in agreement?

I'm pretty sure they would have liked for me to be more social, but at the time I was undiagnosed. They didn't understand how hard it was for me, and as neurotypicals, they never fully can.

S1 Transcribed Responses

S3.3.1.b What did you want instead?

To be alone, because in my early experience people were not to be trusted.

(Q- You remember that from when?)

Very early on.

S3.4 Did you participate in meetings for transition into post-secondary school educational or vocational opportunities?

Yes

S3.4.1 If you participated, please describe your experience in these meetings.

There's not really much to describe. Although at times I felt they were over-estimating me.

(Q?)

I think people see my intelligence and think of it as something that makes things easier for me than they really are.

S3.4.2 Did your parents participate in your transition meetings?

Yes

S3.4.3 How well do you feel your school experience prepared you for post-secondary opportunities such as additional education or employment?

In all honesty—very little.

(Q? What would have been more helpful for you?)

I'm not entirely sure, but you can't really compare the grade school experience with the college experience. They are too different.

S3.5 Is there anything else you would like to tell me about your parent(s) involvement in your academic and social experiences in public school?

No.

S2 Interview Responses

Guide Question #S1: What was your educational experience as a student in the urban public school system?

Subsidiary Questions:

S1.1 Did having an autism spectrum disorder affect your ability to learn? If so, how?

Yeah. When they're trying to explain a project and it has to be done a certain way, I tend to not understand the details—a lot more details. Half the time I would do it in a way that's- like- I'm wrong—I assumed what it's supposed to be – but now I'm, missing this one little detail. Like “No, you're missing this- you need to add this” and I can't find this, what is this? But it's like I could give you the answer – but I can't- I don't see the answer. But if it's not written, I don't know- what do they want me to do? What is it that makes this project acceptable? I don't see that detail.

S1.2 Describe the classes or learning environments in which you felt successful.

I remember, the kind of like the prep colleges- the prep classes to get into college. (Q?) English. (Q?) They felt simple. You know—I do my assignments – if they give me assignments I do my assignments. Then on the weekend I have a lab assignment which is like a whole – simply done- explained on paper – I would answer questions, or learn a few phrases. Then take a test on the computer. That on a daily basis felt easy to me.

S1.3 Describe the classes or learning environments that were the most challenging for you.

Full Sail. (Q?) When I took a class I thought it was going to teach me -like how to use the computer, how to use MIA and how to Anime. Instead it's kind of like- okay- “We're giving you this project- make an animation within a week. Here's your computer- Go.” How do I use

S2 Transcribed Responses

this? “You’re supposed to know before you take this class.” (*Q- High school?*) High school...Math—math was the most difficult. (*Q?*) Usually because I have a bad problem with math in which -- I can discover the formula—I can remember what should I do with the formula-- but I still can’t see the answer. I could follow the steps but somehow I miss one part- or screw up on it. And I would be like too high or too low for the answer.

S1.4 What help – if any – did your parents provide with home-learning assignments?

They would review the book with me. I would need someone to- - I know people don’t like me using the phrase, but to me it is the only one to make sense- dumb it down for me. Some of the time I can’t understand what the book’s telling me.

S1.5 What learning accommodations did you believe to be the most helpful?

What does that mean? (*Explained*) Extended time helped for the tests. Because I can not complete a test on a time limit.

S1.6 During your school experience you may have worked with many different teachers.

Without naming any specific teacher or teachers, tell me about the characteristics of those teachers (e.g., sense of humor, classroom management skills, instructional methods) you feel were most effective in helping you achieve your academic goals.

Very patient. They will explain to me no matter how many times I ask the question. Because would miss the explanation, or forget it.

S1.7 You have had many academic experiences throughout your years in school. Please

tell me about a learning experience that you vividly recall. (*Explanation*)

Well, it’s a bit little embarrassing to mention ... but it’s the only one that I can come to my mind. (*Q? Assurance*) I don’t think this has anything to do with my learning disability

S2 Transcribed Responses

but my history class, it took place in the auditorium, and usually we watch movies that represents the information. And it was a dark room, and this was the first class I have in the morning. So I always have a tendency to just—and the room is not all that cold at all it's warm. So I tend to fall asleep during the educational movie. And I force myself to be awake- first thing I know I'm watching this and automatically my eyes kind of shift around like this – and I'm like, How did I get down here? I don't even recall getting sleepy – I just automatically transported facing my head on the floor.

Recalled later:

I just remembered something in high school that I really regret. The art class I took. When I went to this magnet school, I was introduced to this teacher that I was supposed to have, and he showed all this stuff we would be learning, and everything—we would be learning about animation using Flash, which- I worked with Flash- and I'm like- great, this is the class I want to take. The day I took the class, he was taken out and we got another teacher. And she did not teach us Flash at all. The sole purpose I signed in for this school and this class was gone. I always asked “When are we using Flash?”—“Oh, we'll do it soon” and I graduated and we haven't learned it once. This was in high school. We learned Photoshop, and nothing about animation, nothing about—you know just still life's. And I'm like – this is not what I signed up for—this class is exactly the same as commercial art. This is not what I signed up for. I should have gone into commercial art. *(So you were really disappointed?)* I was—I was really kind of like falsed. Like- wanted to take this class on the Flash- I'm not getting a class on Flash, I'm spending my whole time drawing myself in the mirror—that's it. And that's not what I want to learn.

S2 Transcribed Responses

S1.8 Is there anything else you would like to share about your educational experiences in school?

Not much of high school—high school went rather well- math was the only thing that gave me the biggest problem. *(What was the highest level of math you took?)* Geometry.

Guide Question #S2: What was your social experience as a student in the urban school system?

Subsidiary Questions:

S2.1 Did you participate in a social skills class? If so, please describe your experience and any changes you have made as a result.

Psychology doesn't count? *(Psychology doesn't count)* I'm sort of in a class that's about interacting now. *(Now? That's at the college? But in high school?)* No. I just focused on science, all that need-to-know stuff.

S2.2 Did you participate in any clubs and/or after school activities, including senior events (e.g., Grad Night, Senior Prom, graduation)?

S2 recalled another S.1.7 event—go to S.1.7

S2 indicated by head nod that he went to graduation

But just graduation. *(You didn't do Prom or Grad Night?)* Prom is not for me. Grad night- I don't like 'prep' crap- Prep shows and stuff like that. I try to sneak out as much as I can. They'll make us go, but I'll always find a way to just not going.

S2 Transcribed Responses

S2.2.1 If you didn't participate ...

S2.2.1.a Did you want to participate?

S2.2.1.b Who or what kept you from participating?

A lot of things—one of them I don't want to mention at all. But mostly, I'm not good with big crowds. I can't get into a Prep thing. (*Prep?*) The whole loud shows—I can't do that— No, I can't bring myself to do it. But like the other ones I don't want to mention. I'm just not good with big crowds—especially like parties and stuff like that. If there's nobody I recognize or very used to. And even if it's still like family and stuff, I have a tendency to not speak until spoken to.

S2.3 What help did school personnel provide, if any, for your participation in social activities?

A lot of the teachers in high school were very helpful- a lot of them. (*Q?*) They kind of made like a special guide for me to study—like what should I focus on—what I need to study. (*That was academic—what about social?*) Social. I don't think I got any from them.

S2.4 Tell me about the friends you had in school.

S2.4.1 Was it easy or difficult for you to make friends? Please explain.

In elementary school it was pretty much impossible. But high school, I made a couple of friends that I'm still in contact today.

S.2.4.2 How would you classify most of your friends: students with ASD or neurotypicals (without ASD)?

S2 Transcribed Responses

I'm not sure if any of them have the same problem as I do. I don't think any of them have it. But I guess because we see eye-to-eye to many—we have similar interests- we all tend to participate in it—we all like to animate something—so ... (*Assuming without autism?*) I'm assuming.

S2.5 Would you characterize your social experiences in school as mostly positive or mostly negative? Please explain your response.

Neutral. It's just – trust me – it's was all right here. No one got up on my case or anything. No one tried to be mean. This school was good. Unlike elementary school which was something I like to pretend never existed.

S2.6 Is there a social experience you had in school that you vividly recall? If so, please describe what you recall.

In high school—in the high school category, which I'd rather mention than the elementary- was one we altered this program called—this is how actually I met up with and became friends – was when we were in this—There was this thing what we did in a project for school which the art magnet program switched to different classes for a week to learn- to see the other ones. When we did photography we were having to be set up as a group. And then- we were set up as a group and then we started goofing around with the pictures and then I actually was able to – Hey I got these old Halloween costumes I still have. I could bring them one day and then like all right—and then we just bring them in—and then have a time- put on a skull mask , a cape robe, _____, cowboy, go out in the school hallway and have ourselves ridiculous poses or anything... I had a lot of fun with that and since then I've been with these guys. The pictures are hilarious. I wish I was able to have

S2 Transcribed Responses

kept them, but I wasn't allowed to.

S2.7 Is there anything else you would like to say about your social experience in school?

No. I didn't talk too much. Other than to the art magnet kids.

Guide Question #S3: What do you remember about your involvement, and your parent(s)' involvement, in your school experience?

Subsidiary Questions:

S3.1 Did you participate in your individual education plan (IEP) meetings?

What kind of meetings are those? (*Explained*). Yeah, I don't like it, but I did.

S3.1.1 If you participated please describe your experience in these meetings.

It feels like an innovation. (*Intervention?*) Yeah, is that what you call it. Having all my teachers in one room at once and talking at me. It feels like, oh God, I don't—am I this dumb that they have to work together to get me to pass? It just feels so awkward. (*You don't like being the center of attention?*) I don't like—I have never been the guy that likes being the center of attention.

S3.1.2 Did your parent(s) participate in your IEP meetings?

I guess I purposely – I don't know- I'm just thinking- The reason why people tend to forget about me I guess because I purposely try to blend out – or rather blend in back .

I'm sorry this is a different topic—Yes (*parents participated*).

S3.2 Was there a time your parent(s) requested an academic experience and/or learning accommodation in which you were not in agreement?

Is that the same thing- the whole group meeting thing? (*Clarification*)

S2 Transcribed Responses

Just them planning the whole intervention thing is something I disagree on. Just the meeting. I would rather not have a meeting—just go about my merry ways. Just try hard. (Q?) I'll admit some of the things helped, but I just didn't like the process of getting it. It feels like—like when you're in school and you've done something horrible – it feels like – it reminds me of elementary school – you've done something horrible and you're in the principal's office and they bring the parents in—it felt exactly like that. And you're a little kid and you're just there with your head lowered down – and like I can't believe this. It felt exactly like that. They say this is to help you- why does it make me feel horrible then?

S3.3 Do remember a time when your parent(s) wanted something for your school social experience in which you were not in agreement?

The didn't make me—but they did ask if I should go- and stuff. (*Did you go?*) No. I – like I said- I don't do Proms or any of that group stuff.

S3.4 Did you participate in meetings for transition into post-secondary school educational or vocational opportunities?

Is that the one where they tell me what's going to happen when I go to high school and they explain about college? Yeah, I did participate in that.

S3.4.1 If you participated, please describe your experience in these meetings.

It was fairly good. They actually pulled off kind of a theme to go with it- in which they based it off- in which the speech is loosely based off a Dr. Seuss book *The Places You'll Go*. And the reason why they did this- cause this same time it was the one hundredth anniversary of Dr. Seuss—and they really pulled it together. (*Was this an individual*

S2 Transcribed Responses

meeting?) Not individual—it was a group of other kids who were about to graduate. It was for the Senior class – and I thought this was actually very well done—well put together.

(More Q about an individual transition meeting). I don't recall.

S3.4.2 Did your parents participate in your transition meetings?

No- that meeting was just me.

S3.4.3 How well do you feel your school experience prepared you for post-secondary opportunities such as additional education or employment?

Pretty bad. *(Q?)* Because I was supposed to learn how to animate on the computer for Full Sail- and I was never taught what I need to learn for Full Sail. I signed up to learn- but I didn't get it. So—when I got sent to Full Sail and I showed Full Sail what to teach me, I'm supposed to go away with already the knowledge – Full Sail does not teach you how to animate. It teaches you how to work as a business- you know- they'll give you a product and tell you how it's supposed to be done. It's supposed to be teaching— The whole point I discovered of Full Sail is preparing you how to work for an animation company. Not how to animate. You're supposed to already know that by now. Which I didn't—so I bombed. And when it comes to technology- I believe I am cursed. And even to this very day there are too many coincidences to make it look like it's all in my mind. I mean, I have gotten super nerds look at my computer, saying like 'Oh that's got to be something simple'. And they look at it and say "Huh. That's is strange, how did it do that?"

S3.5 Is there anything else you would like to tell me about your parent(s) involvement in your academic and social experiences in public school?

No. I have nothing to say

S3 Interview Responses

Guide Question #S1: What was your educational experience as a student in the urban public school system?

Subsidiary Questions:

S1.1 Did having an autism spectrum disorder affect your ability to learn? If so, how?

Would you like me to start at the very beginning of my educational career? *(Tell me however you feel that autism may have affected your ability to learn—that would be fine.)* Starting at the very beginning, which is pre-Kindergarten, that's – to me- that's like the age when it was the worst for me. But my mother was able to find a special education program at G. Elementary School, and my teachers there were very nice. It was a small classroom environment, there were only eight students there – including me- and, uh... *(So, focusing then on the prompt,...)* Oh, yes, I don't think this is really answering the question. I apologize. *(Don't apologize at all. I want to hear all about your experiences. What was necessary for you in a special education classroom at that point? How did having autism affect your ability to learn?)* I think the disorder itself really affected my ability to learn. Even though autism affects not only social abilities but cognitive abilities—being able to learn math or science or knowing how to read or write. Those things—those skills and that kind of knowledge can be taught in a straightforward manner. But it does affect my ability to – sorry, I'm trying to think out my responses carefully in order to provide a meaningful answer that's useful. But hopefully I'll hesitate less as this goes on. As far as education goes, it's an experience that's meant to be – meant to involve everybody. All the teachers, just getting the teachers and students together. There are times when students will need to participate in projects together, and they will need to know how to properly deal with other

S3 Transcribed Responses

students. (*Social aspect affects the ability to learn?*) At least for me it was. I don't know if that experience applies to other students with high functioning autism.

Also, concentration could be involved- the ability for an autistic student to be able to focus on one particular task. Typically individuals with autism may be affected by certain external stimuli. And that may affect their ability to concentrate properly in class. I've learned- over time- I've learned to be able to function in less than ideal situations. I'm sure you're aware that certain autistic individuals—they have a lot of strict preferences that they adhere to as part of their ritualistic behavior patterns. But then- the most important lesson—the lesson that I've learned is that we can't always have what we want. We have to adapt to our situation because the world won't always bend over backwards for individuals that have special needs. They have to be able to adapt to the situations. And it was challenging at first, but eventually it became intuitive, and eventually became a learned behavior pattern.

S1.2 Describe the classes or learning environments in which you felt successful.

High school? (*Yes*) I think I was successful in a lot of classes. I studied very hard and I gave maximum effort wherever I can. (*Particular environment? Way the classroom—kind of teaching going on that you liked better?*) I generally prefer classes that were very personalized. (?) Like – for example- creative writing. That class gave me the ability to express who I was. And to make my talent shine forth, and make other students acknowledge my talents. And then– it helped other students in class to like me better. And I felt comfortable and happy.

S1.3 Describe the classes or learning environments that were the most challenging for you.

S3 Transcribed Responses

Is there a particular time limit that I must adhere to? *(No... I just don't want you to have to spend all day with me... we have a lot of questions.)* Okay, I hope you find this information useful in your research.

I would have to say—strict or restrictive environments in which a – well I would say behaving in class was never a problem with me. But it did make me feel nervous and apprehensive being in that kind of strictly regimented classroom setting in which behavior for students was—I'm trying to find the right words – Would you like me to extrapolate a bit more? *(I understand the meaning of what you're trying to say. The rigid, dictatorial kind of learning environment was not a good situation for you- you didn't thrive as well there.)* There are a couple of things that need to be clarified more-- other things that pop into my head at later moments – we can go back just in case. *(assurance given).*

S1.4 What help – if any – did your parents provide with home-learning assignments?

As far as academics went, they weren't really able to help me that much mostly because of their limited academic background. My father, he had a high school diploma but he had to drop out of college early because his mother had died and he couldn't have financed his education any more. And my mother, she went to nursing school so she was able to get a pretty solid educational background, but most of that knowledge was not retained in later years. So for classes like calculus or physics or biology- well, maybe some in biology, but most of the advanced topics like microbiology she wouldn't have been able to help me with.

S1.5 What learning accommodations did you believe to be the most helpful?

S3 Transcribed Responses

Extended time was definitely very useful. It helped me to focus and concentrate more on what I needed to accomplish. And not being around other students also helped me to be in my own zone so that I can get what I needed to do done.

S1.6 During your school experience you may have worked with many different teachers. Without naming any specific teacher or teachers, tell me about the characteristics of those teachers (e.g., sense of humor, classroom management skills, instructional methods) you feel were most effective in helping you achieve your academic goals.

Would you like me to name positive and negative aspects? (*Clarified that I asked about characteristics that were most helpful*). Well, like any other teacher for NTs, just a lot of encouragement, understanding, empathy. I think we can agree that even for NTs those are necessary attributes for teachers. I understand that, that- you know because this isn't an ideal world, teachers can't always have these qualities. Maybe because they're under unique circumstances, or they're stressed out, or they don't have enough experience in dealing with students that need an unconventional form of instruction.

S1.7 You have had many academic experiences throughout your years in school. Please tell me about a learning experience that you vividly recall.

Are you referring to something that's out of the ordinary? (*Restated the question.*) I think I've been away from high school for too long. I'm trying to go over each year that I've been to- I try to go over every year that I've been through, and right now nothing seems to come to mind.

S1.8 Is there anything else you would like to share about your educational experiences in

S3 Transcribed Responses

school?

For high school or any school? (*Any school.*) I didn't always understand it at the time- I simply went to school to learn, and that's what the function of the school is. It's a center for higher learning- to learn about diverse subjects that's- that would be needed for- not just for careers but also because education is meaningful. Being able to learn about the world. We learn—School also helps us learn about ourselves. But students are not alone in their journey. They're in the same boat with many other students. And when you throw together many students from diverse backgrounds- diverse races, cultures, socioeconomic backgrounds- it can be a challenge for them to get along with each other. Sometimes conflicts ensue. It can be hard for Auties or Aspies to cope with these challenging situations. How can they deal with people from different cliques? Or people that think differently from them. (*Q?*) It was a learning process, but it's a process I couldn't have achieved in a vacuum. Like the other students have to be around other people. And they have to push themselves in order to grow. Because in the future they will have to deal with other people, whether they like it or not. They can choose to be loners, if they want to. Personally, I do enjoy the company of other people. But I'm not a really popular person. I wouldn't describe myself as somebody that's "sticky." I don't go around making friends with anybody even though I describe myself as a nice person... nice, friendly. (*Segue into the Social questions—interviewee wants to continue on this track.*) Anyway, to conclude with educational experiences. High schoolers typically say high school isn't not about books or studying. It's about going to football games, going to pep rallies, going to – fooling around... joining clubs, being involved in the community... just enjoying being young. And I regret that I wasn't able to

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fully utilize my high school experience, but now that I'm a lot more mature... if I could go back in time I would tell myself to not worry so much about my – about other people or how I'm doing in school. Just enjoy myself and enjoy the company of other people.

Guide Question #S2: What was your social experience as a student in the urban public school system?

Subsidiary Questions:

S2.1 Did you participate in a social skills class? If so, please describe your experience and any changes you have made as a result.

Well, a long time ago in elementary school I was part of a speech therapy program- for about five years or so. After that, I didn't really need to – I wasn't really part of any – uh—*(no special education classes after that? No social skills class?)* No, but I think it would be useful for me to be part of a debate team, or to enroll in drama.

S2.2 Did you participate in any clubs and/or after school activities, including senior events (e.g., Grad Night, Senior Prom, graduation)?

S2.2.2 If you did participate...

S2.2.2.a In which activities did you participate?

S2.2.2.b Describe your experience as you participated in these activities.

I will try to go through all clubs and societies I was part of. I was in National Honor Society, Phi Beta Chi, Mu Alpha Theta, I was in Bridge Club, I was in Interact—that was a pretty big one—that I was involved in. That's helped me to not only be more involved in the

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community, but also to socialize with other people that's loved helping others the same way that I liked helping others. Being a part of these clubs and societies, I needed efforts to get to know other people a bit more. I was- unfortunately I still felt a bit detached. I wanted to be—I wanted my name to be more known among the other members of these clubs or these activities or societies. They didn't seem – they were familiar—I think most of them were familiar with who I was, but they weren't really close to me. And I felt like—I felt like I wanted to hang around with these guys a bit more because they seemed like they were cool. I just didn't know the proper way of how to do it.

S2.3 What help did school personnel provide, if any, for your participation in social activities?

S2.3.1 Describe any help that you received.

School personnel that were able to help me most were –oh what's it called- the Special Education Department- Disability- Resource Center. So this includes individuals like Ms. B or Mr. H who were—(*clarification of prompt*) They didn't help me directly for participation in school activities, but they did help me deal with – they were familiar with my situation so they – I believe these individuals were well equipped to deal with my own personal feelings. I feel like I could open up with them about how I was feeling- if I was having a bad day I would instinctively go any one of those two. Or if I was going to participate in something else I would try to – if I was going to participate in a social activity I would try to get some useful feedback from them about—Should I do this? What do you think about this?

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S2.3.2 Was this help effective? Why or why not?

I think we really connected on a personal level and that's why our relationship has been able to endure over the years. As you know, the faculty that was really close to me- they continue to talk about me, even though I have been gone for a while.

S2.4 Tell me about the friends you had in school.

S2.4.1 Was it easy or difficult for you to make friends? Please explain.

I was typically around people that were eccentric rather than popular. They were kind of like – well- it's kind of like a mixed bag. I was in a lot of Honors and AP courses, so I did have friends with people that were smart. They were kind of like nerds, and I was kind of like a nerd. And I felt like these were kind of like the right people to have friends with because they were ambitious, they were hard workers, and I felt that- like me- they were driven to succeed and accomplish great things. (*Q? easy? difficult?*) It was still a degree of detachment with them- just because they were- it seemed like they were on kind of a level I can't reach. Maybe I didn't have the same kind of interests that they did. But that was preventing me with breaking the ice with them.

S.2.4.2 How would you classify most of your friends: students with ASD or neurotypicals (without ASD)?

They were the smart, nerdy kids that I was with. They were also- like the misfits and unpopular kids. I wouldn't say they were bad—they weren't bad kids. They were a little- they were like underachievers. I would usually sit with them during lunchtime- instead of the smart kids. Just because they welcomed me- they were always like “Hey, S3- you, know,

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come over here with us.” They liked to just have fun and fool around - engaging in shenanigans and tomfoolery. Just because it’s such a laid-back environment I didn’t have to feel so uptight around them. But they were like- like an eccentric bunch, though. (*Q? ASD? NT?*) I wouldn’t say—I wouldn’t put them into that category, but I think they were weird in some kind of- I think they were weird in some kind of other way. I remember this one guy that I knew in high school. He kind of had—we talked about interests that we shared, like comic books or Anime, or the latest movie. But something was—he would talk about strange stuff with me. Like strange things that he sees, like a shark with five fins, or feelings that kind of- burning, some kind of unexplainable anger or hatred toward society.

S2.5 Would you characterize your social experiences in school as mostly positive or mostly negative? Please explain your response.

My – what question are we on? How would I characterize my social experience? I’d say overall my- first half of my high school started a bit rough. Since it was mostly an awkward phase. And it started to get a lot better in 11th grade. And – okay- social experiences, right? I think overall I continued to get along well with most of the people that I knew. (*so it was mostly positive?*)

Yeah, I- in retrospect I still feel like it was a bit lacking, because there’s that degree of detachment—like I wasn’t really one of them. Like I felt like I was still in a world of my own, pretty much. Mostly because I prefer to do things on my own. Or, I wasn’t really as much—I wasn’t really around other- around my peers as much as I could have hoped. But, that was then.

You know, there’s really nothing I can do about it now.

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S2.6 Is there a social experience you had in school that you vividly recall? If so, please describe what you recall.

If I had to describe the ones I vividly recall—psychologists tend to say that individuals vividly recall the negative or bad experiences the most, just because they're traumatic. And if I had to describe traumatic experiences it would have been PE just because I was never very athletic. I was usually picked last, picked on by other students in that PE class. And even just by some random people that I don't even know. Like they act- like a bunch of immature assholes, and I don't even know why. But apparently high school can sometimes bring out the worst in people. That's not always the case, but...

S2.7 Is there anything else you would like to say about your social experience in school?

This isn't exactly related to my social experience. The best relationships that I developed in high school was not- I did develop very close friendships that still endure to this day. But meaningful relationships that I did develop was mostly with my teachers. Just because I looked up to them, and I felt like I could really open with them. And they're the ones that I really miss most about this school. As for the school itself, I don't really like setting my foot again in this school just because I want to distance myself with my old life here. I feel like I really need to move on with my life. It's not that I don't want to forget about everything—it's just that I'm looking forward to having better experiences in the future, and being able to live a better life rather than this small microcosm that students are unaware of in school. They have no idea what they're in for.

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Guide Question #S3: What do you remember about your involvement, and your parent(s)' involvement, in your school experience?

Subsidiary Questions:

S3.1 Did you participate in your individual education plan (IEP) meetings?

Yes, I was, and so were my parents.

S3.1.1 If you participated please describe your experience in these meetings.

They were very useful for me. I felt comfortable- these were people I was pretty close to. And they helped me plan out my future about ...

S3.1.2 Did your parent(s) participate in your IEP meetings?

Yes.

S3.2 Was there a time your parent(s) requested an academic experience and/or learning accommodation in which you were not in agreement?

S3.2.1 If you didn't agree...

S3.2.1.a Please describe the situation with which you did not agree.

S3.2.1.b What did you want instead?

S3.2.1.c From your perspective, whose request received support from school personnel?

(long pause—prompted) This was a while ago. I remember I was a bit uncomfortable with having accommodations for extended time because, it's – I felt that it would make me feel a bit inferior to other students. I felt like I needed to—I did have it. For they're sake and my own sake I did. I listened to them carefully, and we agreed it would be in my best interest.

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S3.3 Do remember a time when your parent(s) wanted something for your school social experience in which you were not in agreement?

S.3.3.1 If you didn't agree...

S3.3.1.a Please describe the situation with which you did not agree

S3.3.1.b What did you want instead?

S3.3.1.c From your perspective, whose request received support from school personnel?

They wanted me to have a lot of friends, even though I felt I didn't really need a lot of friends. At the time I felt that school was really mostly to learn. I think that the primary function of school is still mostly to learn, but I'm now aware that school does offer a much more broad experience for students to enjoy and immerse themselves.

S3.4 Did you participate in meetings for transition into post-secondary school educational or vocational opportunities?

Yes, and I still attend those today. I still periodically meet with Vocational Rehabilitation officers.

S3.4.1 If you participated, please describe your experience in these meetings.

S3.4.2 Did your parents participate in your transition meetings?

Yes they do.

S3.4.3 How well do you feel your school experience prepared you for post-secondary opportunities such as additional education or employment?

S3 is looking for question on the sheet, interviewer indicates last page

S3 Transcribed Responses

Last page? We're almost done? (*indicates that we've been talking for 45 minutes—S3 concerned about taking too long--*)

I know that there's a lot more that I would have liked to say. If I could have prepared—I should have been more mentally prepared. I'm not nervous or anything. It's just that when I give out responses like this- I try to- I tend to over-think them. I don't always end up giving the responses that I would have liked. (*assures he can take questions home and revise response if he would like*). High school has taught me a lot about different subjects. As far as the real world goes, I don't think it's helped me to find out who I really was. I think that's up to the individual. When I got out of high school, I didn't really know what I wanted to do in my life. And to be honest, well, I'm beginning to have a better idea of what I want to do, but there's still a lot of uncertainties.

S3.5 Is there anything else you would like to tell me about your parent(s) involvement in your academic and social experiences in public school?

They were always there when I needed them. I think that's the best way that I can sum it up. They were always at—if it was for meeting about me, they were always there. Just because they cared about me that much. I'm forever grateful to them for that... their dedication and support. Academic-wise – I was taking classes that were beyond their level, but they were still always pushing me and encouraging me to try my best. And that's exactly what- whether it's Auties, Aspies, or NTs- or any- whether it's anybody on this diverse spectrum, regardless of whatever- of who they are—they always need that kind of encouragement just so they can have the drive and motivation to get themselves going.

S4 Interview Responses

Guide Question #S1: What was your educational experience as a student in the urban public school system?

Subsidiary Questions:

S1.1 Did having an autism spectrum disorder affect your ability to learn? If so, how?

I really don't think so. I mean, I believe I have the same capacity to learn as other students. I mean, I pay attention. In fact I believe I pay attention more than other students.

S1.2 Describe the classes or learning environments in which you felt successful.

I believe I felt successful in classes that weren't really loud. But I can basically adapt to any type of classroom. *(Q? Did the noise bother you?)* Not really, it just made me sometimes lose my train of thought.

S1.3 Describe the classes or learning environments that were the most challenging for you.

Really it's not the classroom that was challenging, it's really what I was learning that was challenging. *(Q?)* Well, to me I believe it was math. That's the most challenging thing for me. But I can still understand math.

S1.4 What help – if any – did your parents provide with home-learning assignments?

Well, they got me a tutor. *(Q? What subjects?)* Math. And sometimes science. And if they could have, they sometimes would have also helped me as well. If they had the time.

S1.5 What learning accommodations did you believe to be the most helpful?

I don't know. I guess sitting in the front. I prefer to sit in the front than in the back. *(Q? Other accommodations?)* Well, supposedly, that I had the helpers to the teachers that would also help

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me. But, they didn't really even done much for me in my assignments. But rather explained me things. *(Sitting in front was the most helpful accommodation?)* I mean, I never really requested the front, I just tried to get to the front.

S1.6 During your school experience you may have worked with many different teachers. Without naming any specific teacher or teachers, tell me about the characteristics of those teachers (e.g., sense of humor, classroom management skills, instructional methods) you feel were most effective in helping you achieve your academic goals.

Hmm. I'm trying to remember. *(Long pause)* Oh yes, my American History—yeah, my American History teacher had a sense of humor. He was also my Holocaust Class / World religions teacher. It helped us understand. I mean it helped us understand, and it didn't make us get bored or anything. *(So a sense of humor was effective in helping you achieve your academic goals?)* I guess so. Yes.

S1.7 You have had many academic experiences throughout your years in school. Please tell me about a learning experience that you vividly recall.

What do you mean? *(Clarification) (LONG PAUSE)*. Can I come back to this later?

(Later):

I do remember, in my Senior year, for my English class that we had to make a Senior Memory Book. Like, to make all the memories we had throughout our school year. *(Q? You enjoyed that?)* Yes. *(Q?)* I found it pleasant. I still have it with me in my room.

S1.8 Is there anything else you would like to share about your educational experiences in school?

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It was great.

Guide Question #S2: What was your social experience as a student in the urban public school system?

Subsidiary Questions:

S2.1 Did you participate in a social skills class? If so, please describe your experience and any changes you have made as a result.

Social skills... what do you mean? (*clarification*) I don't think so. I never told anybody about my- um- I don't know I just didn't want to tell them about it.

S2.2 Did you participate in any clubs and/or after school activities, including senior events (e.g., Grad Night, Senior Prom, graduation)?

For clubs I was in the FFA. (*Q?*) The letters don't stand for anything anymore, but they used to stand for *Future Farmers of America*. And it was basically a leadership program about agricultural stuff. I also participated in the Spanish Honor Society and it was basically helping out the community, making sure its well. And for the school activities, I participated in all three of these Senior events. Especially graduation. (*Q?*) Yes, because if I didn't participate in graduation, I wouldn't be here right now.

S2.2.2 If you did participate...

S2.2.2.a In which activities did you participate?

S2.2.2.b Describe your experience as you participated in these activities.

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Well, I never really had a high position, but I was active in participating. (*Q? Feelings?*) I was satisfied, I guess. I mean, I made friends.

S2.3 What help did school personnel provide, if any, for your participation in social activities?

I don't think they helped me in that area. They just helped me get the best possible education for my classes.

S2.4 Tell me about the friends you had in school.

S2.4.1 Was it easy or difficult for you to make friends? Please explain.

For the first two years I didn't really have any friends. But then during Junior year I decided to, I don't know- step forth and try to make friends. And so I did.

S.2.4.2 How would you classify most of your friends: students with ASD or neurotypicals (without ASD)?

Well, they were normal. I mean- the NTs.

S2.5 Would you characterize your social experiences in school as mostly positive or mostly negative? Please explain your response.

Mostly positive. (*Q?*) Well I tried not to get into any trouble... I focused on my education and make sure my friends were not shady. (*Selective about friends?*) Yes.

S2.6 Is there a social experience you had in school that you vividly recall? If so, please describe what you recall.

(*long pause... sigh*) Can we skip—no wait-- can we come back to this one later?

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Later: These questions are just for high school, right? (*clarification that if something is vivid, then tell about it*) I did have a best friend in elementary school, but he left to another area. I mean, I just wanted to let you know that. (*Do you stay in touch with him?*) Yeah, I stay in touch with him; we're friends on Facebook. I visited him, I think, last year, actually. (*Q? Any other social experience?*) No, not really.

S2.7 Is there anything else you would like to say about your social experience in school?

I don't know... I guess – I guess I did well for a person with this disorder, but I think I could have done better. (*How?*) I don't know, maybe... I mean I had friends but I never really had a best friend.

Guide Question #S3: What do you remember about your involvement, and your parent(s)' involvement, in your school experience?

Subsidiary Questions:

S3.1 Did you participate in your individual education plan (IEP) meetings?

Um, what do you mean by that? (*Clarification*) I know about the meetings—yeah, I went to most of them.

S3.1.1 If you participated please describe your experience in these meetings.

I guess they were all right. I mean, I was as good as I can be. (*Q?*) I felt comfortable, basically.

S3.1.2 Did your parent(s) participate in your IEP meetings?

Yeah, they were also in these meetings as well.

S3.2 Was there a time your parent(s) requested an academic experience and/or learning accommodation in which you were not in agreement?

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S3.2.1 If you didn't agree...

S3.2.1.a Please describe the situation with which you did not agree.

S3.2.1.b What did you want instead?

I told them that for most of my classes extra time was not necessary for me. I mean, before I actually used these extra times, but nowadays I don't use it any more. I don't really need it.

S3.2.1.c From your perspective, whose request received support from school personnel?

I don't think it was on my IEP. *(School personnel supported your request?)* Right.

S3.3 Do remember a time when your parent(s) wanted something for your school social experience in which you were not in agreement?

I don't think so. I wanted to have a normal social life.

S3.4 Did you participate in meetings for transition into post-secondary school educational or vocational opportunities?

S3.4.1 If you participated, please describe your experience in these meetings.

S3.4.2 Did your parents participate in your transition meetings?

I think I remember that. They showed me posters about – after I'm done with high school I can do this and that. Things... *(Individual meeting? Introduced to Vocational Rehabilitation?)* I was introduced to it, but I think my parents were there as well.

S3.4.3 How well do you feel your school experience prepared you for post-secondary opportunities such as additional education or employment?

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I think they prepared me very well. (*Elaborate?*) Well, C.R. is a good school. Especially when you compare it to most schools around the area. (*Were you in a magnet?*) I was in Agri-science.

S3.5 Is there anything else you would like to tell me about your parent(s) involvement in your academic and social experiences in public school?

Well, what do you mean? Like, if they were with me for anything? (*Clarification*) I was like most teenagers. I didn't want my parents to be, like, on top of me for everything. (*Independent?*)

Yeah.

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Guide Question #S1: What was your educational experience as a student in the urban public school system?

Subsidiary Questions:

S1.1 Did having an autism spectrum disorder affect your ability to learn? If so, how?

I think in some ways it did, because I had trouble with abstract thinking, and I had a lot of trouble with art because of my fine-motor problems, and handwriting. I mean, other kids used to make fun of me because I couldn't draw. I was also not good at sports. I was very uncoordinated. In fact, students used to make fun of me because I couldn't kick a ball. This was in elementary school. And, yeah, it did affect my ability to learn in some ways.

S1.2 Describe the classes or learning environments in which you felt successful.

I felt successful in learning environments, probably, where the teachers were very structured and explained things clearly. Like if, like in my junior year I had this Algebra 2 teacher who explained things very well. She would always very give good notes and stuff, and I really, really liked her.

S1.3 Describe the classes or learning environments that were the most challenging for you.

Oh gosh. High school, the two most challenging classes for me were Chemistry and Geometry. Geometry because, well, the teacher was very good, but she was demanding. And I even got a D one quarter. And that really affected my self-esteem, about how I learned. And the drawing stuff too. Shapes and stuff- you had to construct and stuff. Chemistry was hard basically because it

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involved a combination of math and science. (*What was your best subject?*) I didn't really have a best subject, to be honest. There were subjects I did better in, and subjects I did not so great in.

S1.4 What help – if any – did your parents provide with home-learning assignments?

What do you mean by that? (*Clarification*) I actually did have a tutor all throughout middle school and high school. She helped me mostly with science. Yeah, it was – she was actually very good. And she helped me a little bit through college. (*Organization?*) I'm pretty organized, yes. I like organization. But she helped me also get ready for the Math SAT. 'Cause she's an SAT tutor.

S1.5 What learning accommodations did you believe to be the most helpful?

Well, um, I got extended time for tests and assignments. (*Was that the most helpful?*) I can't really think of any others. I'm sorry (*interviewee whispered*).

S1.6 During your school experience you may have worked with many different teachers.

Without naming any specific teacher or teachers, tell me about the characteristics of those teachers (e.g., sense of humor, classroom management skills, instructional methods) you feel were most effective in helping you achieve your academic goals.

Um, it's hard to say 'cause I've had a lot of different teachers with different personalities. Well, like the one I told you about before, the Algebra 2 teacher, I liked her—I liked her characteristics because she was very organized, very structured, very detailed. And the same year I also had a Social Studies teacher who was like the opposite. I didn't like the way he taught at all. I didn't think he was much of a teacher. And there was this project I did at the end of the year. It was actually on autism. And for some reason he decided to give me a bad grade because—he decided

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not to grade me because I chose not to do an oral presentation because I hate giving them. And I was like, really? I didn't like his teaching methods at all. (*Clarification of bad grade*) I'm not sure exactly. Maybe my mom can explain it better. Yeah, there were only a few teachers I really liked. I felt most of my teachers didn't really understand me. (*Q?*) Just, I don't know, the way I like to learn and stuff. (*Which is?*) I like visual stuff. I don't like people who aren't clear.

S1.7 You have had many academic experiences throughout your years in school. Please tell me about a learning experience that you vividly recall.

I don't know, I never really... What do you mean by 'learning experiences?' (*Clarification*) To be honest, I didn't really have one, because I, like I said, I didn't excel in any particular subject. I know, I'm sorry, I can't really answer that question.

S1.8 Is there anything else you would like to share about your educational experiences in school?

I think I kind of took the easy way out as far as, like, classes go. I didn't take any AP classes, or anything. I took a few honors classes, but that was about it. So I guess you could say I kind of—I got mostly B's, some A's and some C's, but for the most part I wasn't outstanding.

Guide Question #S2: What was your social experience as a student in the urban public school system?

This one's hard because I don't want you to judge me on this stuff, because I'm going to be honest. (*Assurance she would not be judged*).

Subsidiary Questions:

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S2.1 Did you participate in a social skills class? If so, please describe your experience and any changes you have made as a result.

What exactly is that? (*Clarification*) I don't think I did. No, I didn't.

S2.2 Did you participate in any clubs and/or after school activities, including senior events (e.g., Grad Night, Senior Prom, graduation)?

S2.2.2 If you did participate...

S2.2.2.a In which activities did you participate?

Not very many, no. I mean, I went to Senior Prom and Grad Night, and stuff. But even at the Senior Prom I was kind of in the background. I didn't dance or anything. And as far as clubs go, well the only clubs I was involved in were Best Buddies, and then most of the parts of my school's chorus. But even though was in it, I wasn't actively involved. I was kind of more passive. (*How do you be passive in chorus?*) Well, I think I just felt intimidated by some of the singers who were really, really good because I felt they had more confidence than me. And I also thought they were very—sometimes I thought they were too self-confident, to the point where it just kind of annoyed me. (*Did you perform?*) Yeah, but not as a soloist. But other than that I wasn't involved in anything else.

S2.2.2.b Describe your experience as you participated in these activities.

I don't know... I mean...like I said I wasn't really actively in them, I was kind of just—I don't know, just a part. I'm answering honestly.

S2.3 What help did school personnel provide, if any, for your participation in social activities?

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I don't know exactly what that question means. (*Clarification*) No, I think I kind of made these decisions by myself.

S2.4 Tell me about the friends you had in school.

Oh my gosh. I don't know, this is going to be really hard.

S2.4.1 Was it easy or difficult for you to make friends? Please explain.

As you can probably guess, it was difficult. (*Q?*) Well, I was kind of a loner. I mean, I had a few friends, but I wasn't very popular, I guess. Like I said, I'm answering honestly.

S.2.4.2 How would you classify most of your friends: students with ASD or neurotypicals (without ASD)?

Do you mean at school? Because I do have other friends who have Asperger's. I mean, the ones at school, no, I don't think they have any disabilities. (*Probe*) I really don't know, I guess maybe—to be honest I don't really have that many friends right now. Because, you know, of my disability. (*Have you been part of a support group?*) You know, I have tried them, but most of them haven't worked out. Like I tried one recently, but I found out something very disturbing about the person who runs it. But I'm not going to go into any detail about that. And it was mostly boys, and I'm not comfortable around boys.

S2.5 Would you characterize your social experiences in school as mostly positive or mostly negative? Please explain your response.

This is hard. I've got to really think here. I've got to be honest. I don't know. If I said it was positive, that would probably be a lie. So I guess it was kind of, I don't know. I don't know if it was positive or negative. To be honest, maybe it was kind of in the middle. Maybe like neutral.

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Because like I said I didn't really have many social experiences. I know that's sad.

(Assurance—Would you have liked more social experiences?) To be honest, without you trying to judge me, no. Because I think too much social stimuli makes me anxious. You know, too much of it. Like, you know. It turns out I almost didn't want to go to Prom because I thought it was too much. But I kind of went anyway, but like I said even there I was kind of in the background. *(Did you enjoy your time at the Prom?)* Yeah, I guess.

S2.6 Is there a social experience you had in school that you vividly recall? If so, please describe what you recall.

To be honest... if I said yes, that would be a lie. No, I didn't really have one. *(Probing)* I mean, there were kids that teased me, if that counts. *(Why would they tease?)* Who knows why. I can never think of any reasons why they would tease me 'cause I never dressed any differently. I always, you know, I think I was always a little more conservative than most of the kids. You know, I wasn't into drinking and stuff. Or drugs, or into sex. I never have been. I never had a boyfriend. Yeah, so that kind of made me feel different.

S2.7 Is there anything else you would like to say about your social experience in school?

No. I just hope you don't try and think negatively of me. *(Assurance)*

Guide Question #S3: What do you remember about your involvement, and your parent(s)' involvement, in your school experience?

S5 Transcribed Responses

Subsidiary Questions:

S3.1 Did you participate in your individual education plan (IEP) meetings?

I think I did, yeah.

S3.1.1 If you participated please describe your experience in these meetings.

Well, I didn't really get to explain much. But basically the teachers just made accommodations and stuff. I didn't have an IEP, I had a 504 Plan.

S3.1.2 Did your parent(s) participate in your IEP meetings?

Yes.

S3.2 Was there a time your parent(s) requested an academic experience and/or learning accommodation in which you were not in agreement?

I'm trying to think. I don't think there was. Although I do have the feeling they sometimes tried to get me involved in things I wasn't too interested in. They tried to get me to participate in a drama class, but at the time I wasn't really interested. But I eventually I ended up taking that class in, I think, 10th grade. But I felt, I only did it because they kind of suggested it. And I was too shy to be involved in that kind of stuff.

S3.3 Do remember a time when your parent(s) wanted something for your school social experience in which you were not in agreement?

No, Although I do have the feeling they sometimes expected more of me socially. Like they would get frustrated with me that I didn't have any friends. At my perception of it. I don't know. *(Probe- school social experience?)* Not really. But I think they would sometimes get concerned with me if I sat by myself at lunch sometimes. But- and I wanted to tell them it wasn't a big

S5 Transcribed Responses

deal, but I was worried what they were going to think. That's the problem I have. I always worry- I always feel the need to please others, and I forget about myself. Always been like that. I know everybody says don't worry what people think of you, but I do anyway. And on the contrary, I think most people with Asperger's don't care what other people think of them. But then how come I'm different? (*Everybody's different*)

S3.4 Did you participate in meetings for transition into post-secondary school educational or vocational opportunities?

I don't think I did. I kind of decided on colleges myself. And maybe because I had a 504 instead of an IEP. Because I didn't really need an IEP, and I was never in any special education classes.

S3.5 Is there anything else you would like to tell me about your parent(s) involvement in your academic and social experiences in public school?

There was one person I forgot to mention about. He was this like go-to... He was the head of the autism department and he gave me like a go-to pass in case I needed to see him for any concerns. And I really liked him a lot. (*Kind of help?*) He was kind of educational and he helped me if I had any problems and stuff. I really liked him a lot. He was also involved in Best Buddies. I mean, he worked with autistic kids, but I was never really part of his class because some of the kids were more lower functioning, and I didn't really need that.

APPENDIX J
TRANSCRIPTIONS OF PARENT INTERVIEWS

Guide and Subsidiary Questions are printed in boldface.

Parent responses in standard font.

Researcher prompts and clarifications are italicized within parentheses.

Significant field notes are italicized without parentheses.

P1 Interview Responses

Guide Question #P1: What was your experience as the parent of a student with an autism spectrum disorder in the urban public school system in meeting your child's academic needs?

Subsidiary Questions:

P1.1 Did having an autism spectrum disorder affect your child's ability to learn? If so, how?

I believe it affected his ability to learn because having problems with socialization and making friends and expressing his feelings appropriately would make him get more upset and shut down when something did happen. And that affected his learning because he may not have wanted to go to school the next day or participate in the next class 'cause he was too emotionally anxious.

So it did affect his learning.

P1.2 Describe the classes or learning environments where you believe your child was most successful.

He was always more successful in writing or English , language arts type classes because that was a very strong area for him and something that he really loved. And when you like something you do well at it. But it, as far as like learning environments it was basically where he felt accepted. You know, if the teacher was somebody that was caring and made him feel like it was okay if he was having a bad day then he did better.

P1.3 Describe the classes or learning environments that were the most challenging for your child.

Either – there was a couple of different situations – either related to like mathematics that he simply- it's not that he didn't get it, but was that he probably didn't want to put forth the effort of

P1 Transcribed Responses

taking the time that it needed. And that's something that builds upon earlier stuff. So if you like miss something you have a hard time. And then the other thing would be the challenges in a type of environment where you had to be verbally expressing yourself about your feelings or opinions. Depending on the situation he wasn't always comfortable doing.

P1.4 What help – if any – did you provide to your child for home-learning assignments?

If he asked for help I would help. But it was more, I would say guidance, in terms of if he asked me “What do you think sounds better- this or that” or if he was stuck getting started on something because he's a perfectionist. So he thinks about things so much and tries to plan them out so much that sometimes he just doesn't get going. That's what- those are the type of things I helped - other than if he needed help in elementary school. In middle school or high school only in those type of situations he would ask.

P1.5 What learning accommodations do you believe were most helpful for your child?

He probably would have done better if he had both a recorder and a laptop type situation in high school. And even though in like-elementary school – or something- they evaluated whether he needed to use a computer- they determined that he didn't. Which I didn't think was right, but I was kind of overwhelmed with my life at the time, so I didn't try to fight it or anything. But he's always had a hard time writing – he writes slower- so if he had a keyboard he definitely would have done – I think- better work.

P1.6 During your child's school experience, s/he may have had many different learning experiences. Without naming any specific teacher or teachers, which teacher characteristics (e.g., sense of humor, classroom management skills, instructional

P1 Transcribed Responses

methods) do you feel were most effective in helping your child achieve his/her academic goals?

I think it really was more gearing the instructional methods to whatever the particular needs were at the time. He needed someone that was structured, but yet loving and accepting. You know- someone that would accept him for him, but at the same time would kind of guide him.

P1.7 Your child has had many academic experiences throughout his/her years in school.

Please tell me about a learning experience that you vividly recall.

I don't know. This goes back to like elementary school. He was an excellent writer and reader- you know- since back then. And the teacher he had for those years- three through fifth grade or whatever- really encouraged that. So that kind of sticks out that she would, say, put up his work or have him read it out loud, or that sort of thing. 'Cause I think that really encouraged his love of reading and writing that's carried on.

P1.8 **Is there anything else you would like to share about your child's educational experience in school?**

Just that there was never enough- past elementary school- I never felt like there was enough communication with me as far as how he was doing and what problem areas he may have had. And when you have a child that doesn't speak up and usually doesn't tell you things until after they've already happened – I think there needs to be more interaction between the parent and the teachers. You know even if it's a weekly-or monthly even – just a multiple-choice type thing where they could check off “hey, they're doing great” or “hey, they need more work in this.”

P1 Transcribed Responses

Guide Question #P2: What were your child's social experiences as a student with an autism spectrum disorder in the urban public school system.

Subsidiary Questions:

P2.1 Did your child participate in a social skills class? If so, please describe this experience and any changes in your child you may have observed as a result.

No. But the things is that- not that I'm aware of anyway- but the thing is that my child was not diagnosed till very late. Which is something that kind of upset me because it was easier to just dump him into the 'Hey, you know, he has emotional problems- he's depressed, he's anxious' and I didn't know anything about Asperger. I knew that he was different since he was a few years old. But with all the psychiatrists and all the teachers that were around him it took him getting so severely depressed that he went into the hospital for anyone with any knowledge to say – hey- this is what it is.

P2.2 Did your child participate in any clubs and/or after school activities, including senior events (e.g., Grad Night, Senior Prom, graduation)?

Nothing.

P2.2.1 If your child didn't participate ...

P2.2.1.a Did your child want to participate?

P2.2.1.b Who or what kept your child from participating?

Not that I'm aware of 'cause those social situations scared him.

(Q: He kept himself from participating?) Yeah, yeah...I would say it's more peer pressure than... I'm sure he would have loved to have been able- to have felt comfortable participating.

P1 Transcribed Responses

But since he didn't feel comfortable, I don't think it was—there was anything special – at least that I'm aware of- that was provided for kids with special needs that- if they went and were having a horrible time- or were anxious or emotional- or something- that they could feel safe to get away from that environment, and have someone call me.

P2.3 What help did school personnel provide, if any, for your child's participation in social activities?

Personally, other than a teacher helping him with being able to go to graduation and facilitating things for him, I can't really recall anything else.

P2.4 Tell me about the friends your child had in school.

P2.4.1 Was it easy or difficult for your child to make friends? Please explain.

It was always very difficult, and he made friends like within the classrooms that he participated in. But it was usually more like maybe one person in each class. But since he didn't seek them out after classes ended, then they weren't really relationships that were maintained. In elementary school he had more friends than, of course, middle school and high school – when kids get tougher and meaner.

P2.4.2 How would you classify most of your child's friends: students with ASD or neurotypicals (without ASD)?

Neurotypicals.

P2.5 Would you characterize your child's social experiences in school as mostly positive or mostly negative? Please explain your response.

I think it was negative for him for the most part.

P1 Transcribed Responses

P2.6 Is there a social experience your child had in school that you vividly recall? If so, please describe what you recall.

No, because - I was sort of shut out from – you know, he didn't share a lot of things and I have a very bad memory. So if he did, I don't remember specifics right now. But I know he had mentioned especially in high school about being picked on, or being called "Sped", or, you know- that type of thing.

P2.7 Is there anything else you would like to say about your child's social experiences in school?

No—I just – I tend to think he didn't have that many social experiences in school. Because other than his friendship with "J." I don't—I can't think of anything else.

Guide Question #P3: What do you remember about your involvement and your child's involvement in his/her school experience?

Subsidiary Questions:

P3.1 Did you participate in your child's individual education plan (IEP) meetings?

Yes.

P3.1.1 If you participated please describe your experience in these meetings.

In general, I thought they were positive because it was one of the few times that you get to have one-on-ones with the teachers and with them telling you 'he's doing good in this', or 'he needs more work in that'. So in general they were positive. Yeah, that's about it.

P3.1.2 Did your child participate in his/her IEP meetings?

P1 Transcribed Responses

Very rarely. It was maybe once or twice that he was asked to be part of the meetings. But in general they were done with the parents- either me or both me and my ex-husband depending on what was going on.

P3.2 Was there a time when you requested an academic experience and/or learning accommodation in which your child did not agree?

I can't remember that.

P3.3 Do you remember a time when you **wanted something for your child's school social** experience in which your child did not agree?

Well, I mean, when different events were happening I would ask him if he wanted to be part of it, and didn't—like I would have loved for him to have taken his Senior pictures, but it wasn't something he wanted to do.

P3.4 **Did you participate in meetings for your child's transition into post-secondary** school educational or vocational opportunities?

Yes.

P3.4.1 If you participated, please describe your experience in these meetings.

It wasn't that it was negative, per se. But it almost seemed like they wanted us to push more toward vocational, versus going on to college. At least that was more the experience I had when we met with the person from—trying to remember (*Voc Rehab?*) Yeah- it was almost like they – they weren't encouraging enough for the fact that he wanted to go to college. It was almost more like- learn a trade or something. And that was not something that I was really expecting.

P3.4.2 Did your child participate in your transition meetings?

P1 Transcribed Responses

Yes, he did.

P3.4.3 How well do you feel your child's school experience prepared him/her for post-secondary opportunities such as additional education or employment?

Not very well. But I think that – you know- for most kids the difference between high school and college is very major. Even if you don't have anything- you know- wrong with you. So, I don't think it's ... necessarily something that they're doing wrong. I just think that because of (my son)'s – I guess- the social aspects of not being comfortable in crowds and in ... he didn't go to let's say, MD College's little- whatever they called that first meeting (*Orientation?*) orientation and things like that. Which might have helped. But if you're worried how you're going to react or how you're going to feel, or be uncomfortable being with a big whole group of college students. I don't blame him, I understand perfectly. But there wasn't any—you know the ACCESS Center is very helpful. But I felt comfortable with the ACCESS center at MD College in XX because I knew it was a huge school so the ACCESS center would be huge. But it kind of put me in the situation where I have to drive 20 miles there, and 20 miles back – or whatever- to take him to that school to be able to have those services. If I felt that he could have gone to the one on 27th Avenue, or the one in Downtown and felt as comfortable, it would have been a lot easier for me.

P3.5 Is there anything else you would like to tell me about your involvement in your child's academic and social experiences in public school?

I honestly think that they did the best they could. I think if you- that even if I had had, you know—more money to have sent him somewhere privately, he may not necessarily have gotten

P1 Transcribed Responses

diagnosed there either because, you know... It's that there's not enough awareness of, I guess, from the faculty, teachers, everyone else about every issue. There's just so many things that could happen with a child- and so many issues they can have. Once the psychiatrist says this is what they have, what are they going- why are they going to argue? They just do the best they can with the information they have.

P2 Interview Responses

Guide Question #P1: What was your experience as the parent of a student with an autism spectrum disorder in the urban public school system in meeting your child's academic needs?

Subsidiary Questions:

P1.1 Did having an autism spectrum disorder **affect your child's ability to learn? If so, how?**

Yes. A child with this type of disability has two main conditions- as far as our experience is concerned. One is organization. Which is a must for any student- to be able to organize information that he or she is going to require. To do the test, to do the homework, and so forth and so on. The other is the social aspect of it. Basically they have no social life whatsoever because they are not understood, they do not understand the other children, they have a problem with the body language and recognition. So all of this affects their interaction with other students where he or she may learn- not only behavior but learn other things about even the curriculum from other students. Because of a lack of communication. So most of the communication a child has is at home, you know, or with the teacher, that can or will take their time from the rest of the classroom to point out things and so forth.

P1.2 Describe the classes or learning environments where you believe your child was most successful.

I believe that the classes that were set up for children with learning disabilities helped him out a lot because it was more like a one-to-one and the teachers knew how to handle children with those types of situations better. Though he did have a couple of classes that the teachers—the regular classes that the teachers went above and beyond to try to help. And they made the class

P2 Transcribed Responses

fun – and caught their interest, so he did fairly well in those classes. I believe it was a science class, a health class or something like that where the teachers really helped him out a lot. As a point of example, he had a very good biology teacher, who made biology – believe it or not- fun. And he reacted very positively to this gentleman. He was a young teacher but he was very smart about how he handled the classroom. He brought little animals to the class, and so forth and so on, and he caught their interest – and at least as far as A was concerned, he would come in and talk about the classroom- which he never did about any of the other classrooms- he actually talked about it and you can tell he was into it- it was fun for him. So, that was a very positive experience. Biology, for me, was horrible- for him it was fun.

P1.3 Describe the classes or learning environments that were the most challenging for your child.

I think the larger classroom settings – the auditorium type classrooms. It's a nowhere land- it's impossible. Even though they did have someone that would monitor children with special needs, and all that—but even with that direction it was still very tough. For a child like that it's easy to get lost in a crowd. I mean, that's what they do there- they get lost in the crowd. And the auditorium type classroom is- as far as our experience is concerned- was the toughest thing for him to deal with.

P1.4 What help – if any – did you provide to your child for home-learning assignments?

Well, one of the things my wife is good at is organization, and she did amazing things trying to organize him. With the books, and the binders, and the labels, and the colors. That was her department. She did an excellent job on it. Mostly what I did, I'm an engineer, so my strong area

P2 Transcribed Responses

is math, and that's what I concentrated on. But, again, it wasn't his ability to learn that was really the problem- it was the lack of organization. And it's still a challenge nowadays. Even more so nowadays when he's in college and he's all by himself. Organization is the main challenge. There is only so much that a parent can do, 'cause when they get home, you have to depend on a lot of things. You have to know what the homework is, what assignments, what to do, if he wrote it down in the agenda, if he didn't write it down, if the right paper's there. Sometimes it's so frustrating you wish you could be in the classroom with them just kind of like poking them saying, "Okay- pay attention to this. However, to the high school credit they did have- whenever it was working- they did have the internet connection. And that was helpful because we keep aligned what was going on in certain classes. And even though at the time the program was in its infancy- I mean they were just starting. And now I understand it's very- Our little girl is excellent because she's in middle school now. We get contact- we get information all the time and e-mails from the teachers continuously. Which wasn't available at the time at that extent. And it's very helpful, actually.

P1.5 What learning accommodations do you believe were most helpful for your child?

The smaller classroom—more one-on-one environments. And I think that nowadays teachers are- just the regular classroom teachers have been more educated to this type of – specially this type of learning disability that before was kind of foreign to them. I remember when A was in middle school they didn't even know what it was. They were kind of learning- we were all learning at the same time. Where now teachers are better informed, and I think they know how to deal with those situations better.

P2 Transcribed Responses

P1.6 During your child's school experience, s/he may have had many different learning experiences. Without naming any specific teacher or teachers, which teacher characteristics (e.g., sense of humor, classroom management skills, instructional methods) do you feel were most effective in helping your child achieve his/her academic goals?

Yeah, this one, like the sense of humor, the teacher that makes the class fun. I think in general most kids relate to that better than – and teachers that are I guess somewhat organized themselves that can kind of—you know... He had an English teacher—she was a very cool lady—a very nice lady- an older lady. But she was very fun, and smart—very smart—and he did well in her classes.

P1.7 Your child has had many academic experiences throughout his/her years in school. Please tell me about a learning experience that you vividly recall.

Other than the science teacher – the math teacher – she was very good, too. She sat him right in the front- kept an eye on him. And he learned a lot in that class.

P1.8 Is there anything else you would like to share about your child's educational experience in school?

In junior high, he was in a private school. It was a disaster. For many reasons. Actually the public school part has been very, very positive. The private school was a disaster. And it was a disaster because of the way he was handled—his condition. In this particular school the parents- - the teachers were also parents of the kids. What happened is in a nutshell, the teachers went home and discussed the problem, and the students were there. It made S2 a target. By the time

P2 Transcribed Responses

we found out, the kid had gone through hell and back, you know. he was bullied and abused—and it was very destructive. In public school that didn't happen because, number one, it was a very large school and he was able to move around without being labeled. And the kids were just doing their own thing – and it wasn't a small school like a private school. So as far as public school is concerned, as far as S2 was concerned, it was very positive.

Guide Question #P2: What were your child's social experiences as a student with an autism spectrum disorder in the urban public school system?

Subsidiary Questions:

P2.1 Did your child participate in a social skills class? If so, please describe this experience and any changes in your child you may have observed as a result.

No. But he's had- he's been involved in therapy groups- but not social groups- and not within the public school setting.

P2.2 Did your child participate in any clubs and/or after school activities, including senior events (e.g., Grad Night, Senior Prom, graduation)?

Not that I know of.

P2.2.1 If your child didn't participate ...

P2.2.1.a Did your child want to participate?

He never brought it up. At certain times I would ask- but he would rather not.

P2.2.1.b Who or what kept your child from participating?

P2 Transcribed Responses

Probably his inability to relate to other kids, and to communicate, to understand. He had friends, but mostly because there was a common ground- and that was the art. So some of his friends are still around- but basically because of the arts. That was their common ground. They connect through on-line and things like that—and they still do. It's not like a one-to-one let's go to the movies. It's more of a- of an artistic connection. They talk about—they don't actually go out at all. Even one of them is in New York, and they still communicate through the internet. they exchange artistic views and so forth. That's the one common thing that they have.

P2.3 What help did school personnel provide, if any, for your child's participation in social activities?

None. Not that I can recall.

P2.4 Tell me about the friends your child had in school.

P2.4.1 Was it easy or difficult for your child to make friends? Please explain.

It was difficult. Extremely difficult.

P2.4.2 How would you classify most of your child's friends: students with ASD or neurotypicals (without ASD)?

No—I don't think—I'm not really sure. I don't think that they were autistic at all. I think that basically what they shared was the love of the video games and the art. But, I remember—and I think that's the one he's still in contact with that —Ms. (*Special Education Program Specialist*) said- I never asked- but there was something there that she knew of the kid – so it might be someone that was in her program as well.

P2 Transcribed Responses

P2.5 Would you characterize your child's social experiences in school as mostly positive or mostly negative? Please explain your response.

It was non-existent. So I wouldn't be able to say negative or positive. It was non-existent.

P2.6 Is there a social experience your child had in school that you vividly recall? If so, please describe what you recall.

What- this is like throughout his school? Because there were actually negatives in the private school. The experiences there were... very negative. There was a little girl in high school—who was also part of the program – 'cause I know because of *Program Specialist* knew her well also... that developed that kind of – well- love relationship. But it went sour—didn't work out. So that's the only one I can recall.

P2.7 Is there anything else you would like to say about your child's social experiences in school?

I wish there would be a little more of them. Yes, yes.

*Guide Question #P3: What do you remember about your involvement and your **child's** involvement in his/her school experience?*

Subsidiary Questions:

P3.1 Did you participate in your child's individual education plan (IEP) meetings?

Yes.

P3.1.1 If you participated please describe your experience in these meetings.

They were very good—they had a lot of recommendations – a lot of—you know, when we left the meeting we felt things were going to be adjusted and to work out for him. But somewhere

P2 Transcribed Responses

along the way there was no action. It didn't come to fruition... but the recommendations were very good. They were very – and we went to that, and I remember saying 'Hey, if they implement this!' but at least in S2's time it was never really truly implemented. Somewhere along the line it lost—it got forgotten.

P3.1.2 Did your child participate in his/her IEP meetings?

Yes.

P3.2 Was there a time when you requested an academic experience and/or learning accommodation in which your child did not agree?

No... the one thing that we talked about was for him to have someone in the classroom – one of the students- kind of be helping him out and giving him notes or stuff like that. And that never – I don't remember ever that really happening. I don't know if it was part of his own choice not to be singled out in the class.

P3.3 **Do you remember a time when you wanted something for your child's school social experience in which your child did not agree?**

P3.3.1 If you didn't agree...

P3.3.1.a Please describe the situation with which you did not agree.

P3.3.1.b What did your child want instead?

P3.3.1.c From your perspective, whose request received support from school personnel?

Yes, there has been. Because I'm one of those that pushes for that – and he says "No, Mom".

No – I don't push him- I just tell him what he can do... but even he's been through... You know

P2 Transcribed Responses

he's had therapy. And basically he's never—you know I read up on all of this with Asperger and there's Occupational Therapy. He's never really done any of that, basically he has had psychologists and regular meetings with them and all that. But there's been like groups- social groups- and with CARD here at University of XXX and all that—but he's always kind of shied away from that. I'd rather not—I'm not ready—and no, he didn't want to do it.

P3.4 Did you participate in meetings for your child's transition into post-secondary school educational or vocational opportunities?

Yeah, we did have one meeting, but that was it.

P3.4.1 If you participated, please describe your experience in these meetings.

We did have one meeting at the high school- towards the end. I don't remember that one. There was someone from the vocational school—some information – but no, we never followed up on that.

P3.4.2 Did your child participate in your transition meetings?

No, I don't remember.

P3.4.3 How well do you feel your child's school experience prepared him/her for post-secondary opportunities such as additional education or employment?

Not well at all. I think he was not prepared. I mean—I realize that academically he knew the subjects. But he had no idea what he was going to face-- in higher education ... absolutely no idea. It was like, you know- if you transplant to the planet Mars, for him he was totally, totally, completely lost. And we should have done something to prepare him for that. And we didn't. And, you know we were just kind of bumbling around, trying to come up with an answer for

P2 Transcribed Responses

questions we didn't even understand ourselves. That's what happened. So, in hindsight I think maybe what we should have done was bring him into *Local Community College* before he went—just like we mentioned before. That way we could have kind of kept him here, and kept an eye on him and organized him a little better. Once he had gotten used to the actual level of—maybe he would have had a better chance at a place like Full Sail. But it was – he was set up to fail. There was no way for him to make it. But it was a learning experience for all of us.

P3.5 Is there anything else you would like to tell me about your involvement in your **child's** academic and social experiences in public school?

Gosh, I don't know. We kept in touch a lot with the school. You know, through e-mails and being there at the school whenever we had the meetings—Academically, yes, but socially – there was no social life observed.

P3 Interview Responses

Guide Question #P1: What was your experience as the parent of a student with an autism spectrum disorder in the urban public school system in meeting your child's academic needs?

Subsidiary Questions:

P1.1 Did having an autism spectrum disorder affect your child's ability to learn? If so, how?

Yes, I do. It affects his ability to learn socially. That was his number one problem-socialization. Not so much academically because he did great with academics, although at some point he really has to focus in order to learn better.

P1.2 Describe the classes or learning environments where you believe your child was most successful.

Usually he learns better in a quiet environment. He wants to be in front of class and because the noise distracts him.

P1.3 Describe the classes or learning environments that were the most challenging for your child.

I think what I can remember is the group projects. He thinks that he can do better doing the projects on his own – as far as I can remember- and that he doesn't trust other students because he would always say that they were laid-back, and he doesn't join groups- he always ends up doing it on his own.

P1.4 What help – if any – did you provide to your child for home-learning assignments?

He usually does his own homework, but I'm just there to support him and just to make sure that he manages his time doing his homework, and make sure that he's on time doing his homework.

P3 Transcribed Responses

So I- just to make sure he doesn't forget, so he always has his daily journals. I want to make sure that he flips his daily journals and what's going to be done today or tomorrow.

P1.5 What learning accommodations do you believe were most helpful for your child?

Here in school? (*clarification*)The preferential sitting. The extended time he seldom used it. I think like a couple of times only. Because he- I always tell him that if you need time you have to use it. But I guess, he always tells me that he doesn't want any preferences – the students will know why he has extended time—at that time he was still embarrassed- he has a disability. That's why he's not using it often.

P1.6 During your child's school experience, s/he may have had many different learning experiences. Without naming any specific teacher or teachers, which teacher characteristics (e.g., sense of humor, classroom management skills, instructional methods) do you feel were most effective in helping your child achieve his/her academic goals?

He has mentioned a specific teacher who has really a good sense of humor, and when he is in that class that he really learns to relax because the teacher is like very- it's more relaxing to him than really some teachers are trying to – instead of rigid. That's it... he always tells me. A couple of teachers he mentioned.

P1.7 Your child has had many academic experiences throughout his/her years in school. Please tell me about a learning experience that you vividly recall.

This is what he told me. I wasn't here. It was one time I think – maybe it's in Ms. S's class (*English teacher*) he was trying to prepare a monologue of Shakespeare – soliloquy. And I

P3 Transcribed Responses

didn't know that he was trying to do that, but I just found out from some of his friends' notes that he of all the students that did it, he's the best one. And thinking about that- I was just saying that you know- facing these people in front of the class- how could he do that? And he borrowed my robe to do it. And we were talking about it- with my husband- and I said- I can't believe it-look at this comments from all the classmates – and one classmate of his says maybe you're going to the acting class.

P1.8 Is there anything else you would like to **share about your child's educational** experience in school?

All in all his education here in XX high school was great—like I said except for his social- which he doesn't have that before and I wish he had.

Guide Question #P2: What were your child's social experiences as a student with an autism spectrum disorder in the urban public school system?

Subsidiary Questions:

P2.1 Did your child participate in a social skills class? If so, please describe this experience and any changes in your child you may have observed as a result.

Not that I know of – no, he didn't.

P2.2 Did your child participate in any clubs and/or after school activities, including senior events (e.g., Grad Night, Senior Prom, graduation)?

P2.2.2 If your child did participate...

P2.2.2.a In which activities did s/he participate?

P3 Transcribed Responses

He belongs to – I think- four clubs. Interact, Honor Society, and Science Club and Chess Club. And he didn't participate in the Senior Prom, although I really told him to go. He said that it's so over-rated. (*How about Grad Night*) Grad night he didn't – only graduation. Oh –yeah—Disney World grad Night- he went. And he enjoyed it, he told me.

P2.2.2.b What feelings and/or thoughts did you have as your child participated in these activities?

I was very happy because he's really grown in his socialization and I always encouraged him to participate and I encourage him to join the clubs. He doesn't want to in the beginning, but I think that you have to try. If you don't try then you don't know- if it's good for you or not. So if its not good then quit—but you really have to try.

P2.3 What help did school personnel provide, if any, for your child's participation in social activities?

P2.3.1 Describe any help that your child received.

Social activities inside of school? Or also outside? (*It could be outside also*) Well he participated in – I think- Walk for Witty at the time, and also Plant the Pride- something like that. And they gave him a t-shirt which he still has. And he's really happy about it. (*Specific assistance?*) No, not really. He just found out that they're asking for students to participate. And I said go ahead. Any social activities in school you have to go. So if he says 'I hope I have people that I know there' and I said, well, there's a lot of people there. You could always try to talk and, you know, you can do that. So, he always needs encouragement, that's what he needs. Because if you don't he would just say 'Oh, I'm not going to.'

P3 Transcribed Responses

P2.4 Tell me about the friends your child had in school.

P2.4.1 Was it easy or difficult for your child to make friends? Please explain.

I think in the beginning of the school year, when he was in 9th and 10th grade, but in the Junior and Senior he met a lot of friends. (*Q- so it was difficult in the beginning?*) In the beginning of the school, yes.

P2.4.2 How would you classify most of your child's friends: students with ASD or neurotypicals (without ASD)?

Without.

P2.5 Would you characterize your child's social experiences in school as mostly positive or mostly negative? Please explain your response.

I would say mostly positive. Especially the end of the school year- in the Senior year because he opened up to friends. He was the secretary of the Interact club, he spearheaded the Walk for Autism with couples of Juniors and Seniors from his class. And I was there with a banner and everything. So, you know, those are the things that I really treasure. And thinking about it that I couldn't believe that he can do.

P2.6 Is there a social experience your child had in school that you vividly recall? If so, please describe what you recall.

I don't know if I would consider it social, but he was, I think, in 10th grade. And he called me at work, like an emergency. So the secretary called me 'P3, your son S3 is on the phone and he said it's an emergency.' So when I was busy, but I answered him and thought he got hit or something happened in school. But he told me that a girl kissed him in the hallway. So he says, 'What do

P3 Transcribed Responses

you think of this? What do you think of this?’ And I say, S3, I’m busy, I cannot say anything right now, I’m so busy- there’s a doctor on the phone. And he said ‘I cannot concentrate with my homework.’ And I said why, what happened... okay tell me. So he said a friend of his met this girl in the hallway and introduced them. So- and the girl said ‘Oh, hi S3. So can we go steady now?’ So he said, Mom, I don’t even know the girl. So she just pushed me in the wall and kissed me. And he said, ‘Do you think it’s love?’ And I said, no, S3, it’s hormone. And he said, no, because I was sweaty, I was describing everything. And – but even till now- the girl called at home, but he doesn’t want to talk to her anymore because – I said that girl is trouble - I’m sorry. (*Clarification*) She had attacked him in the hall- and just introduced... that girl is trouble S3, that girl is trouble. And he said how do you know, Mom. And I said you just told me you were just introduced, and then when your friend turned – she pushed you in the wall and kissed you—what kind of girl is that? And he said, well now I’ve had my kissing experience and it was yucky. My first kiss and it was yucky. But I was saying- and he said from now on I’m not going to pass that hallway, and I’m not going to use the same shirt. And he just throw the shirt away. Isn’t that interesting? Be thinks- because the girl said you look good in that T-shirt. And so he thinks that makes him attractive. And I said, No, S3, I don’t know why she did that to you. I’m going to wait- I’m coming home in two hours- wait for me. But he did (*throw the shirt away*)But that was one of the social interactions that I vividly remember. And even now, every time I talk to him about it he says ‘Don’t remind me of that!’

P2.7 Is there anything else you would like to say about your child’s social experiences in school?

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Everything really turned out right for him, but I- in the beginning really was hard for him in 9th and 10th grade. I really wish a social skills class was there in the beginning.

Guide Question #P3: What do you remember about your involvement and your child's involvement in his/her school experience?

Subsidiary Questions:

P3.1 Did you participate in your child's individual education plan (IEP) meetings?

Every meeting.

P3.1.1 If you participated please describe your experience in these meetings.

It's really, really good because- the teachers were there, Mr. H was there all the time. They laid out everything- the goals for the next year, his problem from before that we have to work out, and so we asked questions and they answered my questions. And at the end of the year the Transition was really, really good. 'Cause Mr. H was the one who suggest for him to- at least to live in a dorm for a year, jut to experience the life in the dorm. And he really enjoyed it as far as I know, 'cause we visit him every weekend and I know he doesn't want that, but I want to make sure he's okay.

P3.1.2 Did your child participate in his/her IEP meetings?

Yes he did, he did.

P3.2 Was there a time when you requested an academic experience and/or learning accommodation in which your child did not agree?

I don't recall... I don't recall.

P3 Transcribed Responses

P3.3 Do you remember a time when you wanted something for your child's school social experience in which your child did not agree?

Well, like I said, the Prom night. I really want him to go to experience. Even his sister and his brother want him to go visit it—You'll have the time of your life... One experience of your life you have to go. But he won't. And I said I'm going to rent you a limo – whatever you want—I want you to go. But he says no. If I did it for his sister and his brother, why would I not do it for S3? I will, believe me. I will work overtime.

P3.4 Did you participate in meetings for your child's transition into post-secondary school educational or vocational opportunities?

Yes.

P3.4.1 If you participated, please describe your experience in these meetings.

His, um, Y. was there- his VR counselor. And he's really, really good. Even now he e-mails S3, they e-mail each other, he calls S3 and talks to him—If he has anything he wants to ask questions. So- and we get closer together, from that on up 'til now. He's still waiting for S3's picture in his office. And like I said Mr. H's suggestion- we followed his suggestion. And we also- what we did was – suggestion even from Ms. B (*Middle schools SPED department chair*) before the transition from elementary to middle school we attended the two days orientation. But besides that we went back to the school and really explored where his class will be, how long it will take him to go there, the timing—he has to be there like maybe 20 minutes before the time of his class because I want him to sit on the front because of that—the destruction. So we did that—we go inside the building where the library is and, you know, we explore so that it will be

P3 Transcribed Responses

easier for him.

P3.4.2 Did your child participate in your transition meetings?

Yes.

P3.4.3 How well do you feel your child's school experience prepared him/her for post secondary opportunities such as additional education or employment?

They prepared him very well. Yeah, with the IEP, and every time he has a problem here— at one time Ms. B (*SPED Dept. Chair*) called me 'cause he had a one time problem with the- I don't know if he mentioned it. I think it's his science class where the electricity failed, and he thinks he did it. And no one could talk to him. So Ms. B had to called me because he think he did it— and the teacher said that it just happened. But I guess at the time he thinks he was touching something and the electricity went off. And so the class was cancelled and someone was saying, 'Who did it? S3 did it.' So, that really bothered him. But there's, you know, always communication with Ms. B or Mr. H to me- to call me because I told them if there's something that they need- if he need me, just to call me. (*Q – Communication was important?*) It was important to me.

P3.5 Is there anything else you would like to tell me about your involvement in your **child's** academic and social experiences in public school?

Well, not so- well the social experience is—the academic experience with him is that – like I said he did really well in school. And I really don't have any problem with that. But the social skills, he really needs encouragement all the time. A lot of encouragement. Because if I don't do it, he will never do it. That's the most important thing. Encouragement.

P4 Interview Responses

Guide Question #P1: What was your experience as the parent of a student with an autism spectrum disorder in the urban public school system in meeting your child's academic needs?

Subsidiary Questions:

P1.1 Did having an autism spectrum disorder affect your **child's ability to learn? If so, how?**

Before I answer the question, let me just tell you one idea. In the course of any student like our son, there are probably three areas – three environments if you want to call it- if you are talking about elementary, middle school, and high school. The answers, in some cases, probably are going to be a little bit different in the three environments. So, when we answer we might specify which of the three environments. *(looking for most vivid- but focus is on high school)* If you think about it, any study to help other students, you have to start from the beginning. Although, yes, for high school it's great because it's going to help. But they have already made their minds, their ways for studying, and all that. So, that's where it starts. From the beginning, in elementary. *(Discussion of purpose of study)* For the record, S4's elementary school –*(school named)* excellent school. Then he went into, just for a few months, into a terrible school. It was a Catholic school and it was terrible. It was the worst school, and we took him out of that school and put him in S. Middle School- which was an experience because after a couple of weeks he was there – what happened in S school- a kid was killed in the bathroom- and S4 was there at the time. It was a shock for him—I mean it was terrible. But it was an experience. But at CR High school- excellent school. Okay, all right, so, that's the background. *(Restated the first questions)*

P4 Transcribed Responses

No. Definitely not. On the contrary, I think being an autistic child, some of the things he has is the memory is probably developed more than other kids. He has a good memory.

P1.2 Describe the classes or learning environments where you believe your child was most successful.

Classes? Probably at the time mathematics or history. Probably that was in school what he was good at it. When we say history, and maybe there are some other questions later on, he was also into TV programs such as the History Channel and Discovery Channel that helped him a lot.

P1.3 Describe the classes or learning environments that were the most challenging for your child.

I would probably say, probably the – how he – the transition from elementary to middle school.

It was –it affected him a lot that transition. Okay, and the same in middle school, that's a big problem there because the children there are getting into other age stages, and they are cruel.

Especially with some people with disabilities. They are very cruel in middle school. So elementary was great, middle school was bad, high school was great. (*What was the challenging aspect of middle school—size of school? , the nature of the students?*). All of that, and especially the kids are going from children to junior adults.

P1.4 What help – if any – did you provide to your child for home-learning assignments?

Well, one thing is that my wife is there all the time, helping him, getting after him, trying to sit with him if he needed it. So, that's basically- she was on top of that.

P1.5 What learning accommodations do you believe were most helpful for your child?

P4 Transcribed Responses

Learning accommodations—being next to his sister—no, just kidding. (*Interviewee chuckles—Q? Are they twins?*) No, let me tell you something. I think she was a big factor in S4's accomplishment in what he is right now. She didn't know S4's autistic problem until probably middle school- she didn't know—it was her sophomore year in high school she found out. So it was- by not knowing he was treated like any other regular person in the house. And that- she helped, especially at home, you know, quite a bit. So when you say learning accommodation, we say he was treated like any other child—any normal child if you put it that way. (*Age of ASD diagnosis?*) He was three years old.

P1.6 During your child's school experience, s/he may have had many different learning experiences. Without naming any specific teacher or teachers, which teacher characteristics (e.g., sense of humor, classroom management skills, instructional methods) do you feel were most effective in helping your child achieve his/her academic goals?

Academic goals—well he didn't have any academic goals until later on. (*Helping him achieve in class?*) Well, probably in high school, he had very good instructors – especially in the area—he got into the Spanish clubs. His Spanish is not that good, but he wanted to learn more, and he went into Heritage Club, the Spanish club, and the teachers there helped him a lot. (*Specific characteristic about those teachers?*) The fact that they loved him and guided him and they always protected him. Yes, there was also an advisor who helped him a lot, she loved him and protected him with everything. There was another assistant who was very good- helped him a lot. He always looked into the classrooms, and watching him and all that. And he even called us

P4 Transcribed Responses

because the transition of S4 going to where he is right now - at the end it was difficult. Because he is growing, so he is more stubborn – so Mr. S helped a lot. *(So to characterize: Caring? Compassionate?)* Yes, yes. They loved him over there.

P1.7 Your child has had many academic experiences throughout his/her years in school.

Please tell me about a learning experience that you vividly recall.

Probably something related to—that’s why he got into CR high school. He was into being a Vet, so he was more into the animals, and all of that. So he used to watch, as I said before, the Discovery channel and all of that- because he was very interested. His memory—he used to tell us everything about animals, so I would say that would be a learning experience for him, you know, that brought him into that area because it was in the Agri-science program that brought him into the high school.

P1.8 **Is there anything else you would like to share about your child’s educational experience in school?**

Just related to learning, not necessarily because we are more in the social area, that’s the area we will have more to say. The educational experience in school, as I said before, the transition between one elementary school into middle or to high school. That was probably an experience- being more independent probably in high school than the other, either elementary or middle.

Guide Question #P2: What were your child’s social experiences as a student with an autism spectrum disorder in the urban public school system.

P4 Transcribed Responses

Subsidiary Questions:

P2.1 Did your child participate in a social skills class? If so, please describe this experience and any changes in your child you may have observed as a result.

No, I don't think so.

P2.2 Did your child participate in any clubs and/or after school activities, including senior events (e.g., Grad Night, Senior Prom, graduation)?

P2.2.2 If your child did participate...

P2.2.2.a In which activities did s/he participate?

P2.2.2.b What feelings and/or thoughts did you have as your child participated in these activities?

We mentioned before- the Heritage Club, the Spanish Club. He was also in the – like the Government type- like the Chaplain- where he would have to run everything, and he wa in the Agri- Science club- not a club, that was the magnet. He was in the FFA—Future Farmers of America. He was the Chaplain there in the FFA- one year, in the first year. Also in middle school he was part of the band. He also attended Grad Night, Senior Prom, and graduation. I think it was Grad Bash, not Grad Night. (*Tell me about his experience in these activities*) He was happy- he said ‘Mommy go away! Leave me here! So GO!’ He wanted to be alone like every other child. (*What were YOUR feelings and thoughts?*) We were thrilled about it, and also concerned about his involvement there- what his social involvement there was going to be. Since that’s an area that we are still concerned.

P4 Transcribed Responses

P2.3 What help did school personnel provide, if any, for your child's participation in social activities?

P2.3.1 Describe any help that your child received.

Probably- the Agri-Science teacher- I think she helped quite a bit. Because she was head of that FFA group, whatever. She was always trying to get S4 involved in these kind of activities. She was encouraging. She was a good, good person. (*Was she aware of his autism?*) Yes. All the teachers were.

P2.3.2 Was this help effective? Why or why not?

Yes.

P2.4 Tell me about the friends your child had in school.

P2.4.1 Was it easy or difficult for your child to make friends? Please explain.

Very difficult. Very, very, very difficult. I think he has as friends more girls than boys. The girls love him. But he doesn't know them... he doesn't even keep records I mean telephones, whatever. But he has friends like on Facebook. But the girls are more nicer to him, the guys would usually pick on him. But like in high school I would check on his Facebook page and the guys would say 'Hey, what's up Homeboy?' and I thought okay, the guys are somewhat nice. But he'll avoid the contact, he'll say like 'I'm good' but he won't continue the conversations- he can't continue the conversations, he's not that social. But he tries, and he has people that care about him, from what I notice. His yearbook has a lot of signatures and comments – very good comments. So maybe in high school he made all these friends, but he never introduced us to them. Never. I met a couple, because I would sort of stalk him at school, but he doesn't like me

P4 Transcribed Responses

being around him and his friends because I'm an embarrassment, apparently (*sister's comment*).

I'm two years older.

P2.4.2 How would you classify most of your child's friends: students with ASD or neurotypicals (without ASD)?

No, without. Without autism.

P2.5 Would you characterize your child's social experiences in school as mostly positive or mostly negative? Please explain your response.

Hmm. I would probably say we don't know. That's the problem is that we don't know the result- we don't know what he accomplished. I would say positive, but it's an unknown for us.

P2.6 Is there a social experience your child had in school that you vividly recall? If so, please describe what you recall.

I would probably say in middle school he had a friendship with a boy. J... It was—and he had a friend in elementary, also. But other than that, we don't know any friends in high school.

(*Recollection?*) Since we don't know the results, we don't know of anything positive or negative. (*Q? He doesn't share?*) No. One thing we could consider positive is that can still be friends with his elementary best friend. I know they still talk and text and everything. And he's at the university, also. He is in Jacksonville. (*Is this a young man with autism?*) Yes. The same age. Both him and S4 were on top of all the others. The high functioning, those two.

P2.7 Is there anything else you would like to say about your child's social experiences in school?

He is very independent, right. And maybe one of the social experiences is probably with

P4 Transcribed Responses

the teachers, that he was very good with teachers. And all teachers loved him.

Guide Question #P3: What do you remember about your involvement and your child's involvement in his/her school experience?

Subsidiary Questions:

P3.1 Did you participate in your child's individual education plan (IEP) meetings?

Always.

P3.1.1 If you participated please describe your experience in these meetings.

Very good, because it brought up things that he needed help. You know, I think it was excellent- all the meetings- the elementary school and the high school.

P3.1.2 Did your child participate in his/her IEP meetings?

Only in high school.

P3.2 Was there a time when you requested an academic experience and/or learning accommodation in which your child did not agree?

P3.2.1 If you didn't agree...

P3.2.1.a Please describe the situation with which you did not agree.

P3.2.1.b What did your child want instead?

Yes. We wanted for him to get more time with his exams, and he didn't want to. Extended time.

P3.2.1.c From your perspective, whose request received support from school personnel?

P4 Transcribed Responses

He got extended time. If he asked he would have gotten it, but he didn't want to be different from the other children.

P3.3 Do you remember a time when you wanted something for your child's school social experience in which your child did not agree?

Actually- no, nothing that we have covered in any of those meetings.

P3.4 Did you participate in meetings for your child's transition into post-secondary school educational or vocational opportunities?

Yes.

P3.4.1 If you participated, please describe your experience in these meetings.

I think they were very good helping him to see other options, and he discussed those with us.

We were involved in that.

P3.4.2 Did your child participate in your transition meetings?

Yes.

P3.4.3 How well do you feel your child's school experience prepared him/her for post-secondary opportunities such as additional education or employment?

That post-secondary idea- university, college, is very different for anybody. Not only for those with disabilities, anybody. (Q?) Good. Not excellent, but good. High school yes. But what I was starting to tell you is that university is different. I think there should probably be other courses similar to college that should given in high school. You know, the type of what they have in math- where they talk about the chapters or whatever, but they leave everything for them to study and they have a different result. It's a little bit different than high school. It takes time

P4 Transcribed Responses

for him to adapt to everything. They should have maybe some type of course, or something, to show the students how college is. You know they go—and it happens to all of us. There should be something there, I think.

P3.5 Is there anything else you would like to tell me about your involvement in your **child's** academic and social experiences in public school?

Any more than what we have said before, no, I don't think. The only thing I would probably say is very, very important is the involvement of parents with children. Very important. We, I think we have tried – I don't know if we have succeeded- but we have tried to be involved in everything. That is something that, like any other parent, very concerned in the beginning. While he was growing its other concerns. You know, and we keep thinking about it. Right now, you know, for him—it's never going to stop.

I would like to share with you the first time that they gave us the diagnosis for autism for S4. I know about it because I saw a movie, but my husband didn't know about it. So I tried to help, I talked to him. So, we had to do something. I had to do something. My English is not perfect, okay. At that time we went to Georgia, and I went to a seminar in autism for the kids. There was that lady they made a movie for her, Temple Grandin. The one explaining everything about the box, that her mother helped her. My mind was, you know, 100% in English, I understand everything. I tried to put that in- I bought a book and we read. So we tried to know and get guidance about autism. So, yes, she was an inspiration. As I said, parents have to be very involved, yes. Have to be involved. It's very important.

P5 Interview Responses

Guide Question #P1: What was your experience as the parent of a student with an autism spectrum disorder in the large urban public school system in meeting your child's academic needs?

Subsidiary Questions:

P1.1 Did having an autism spectrum disorder affect **your child's ability to learn? If so, how?**

Yes, I do. It affected her ability to learn in several ways. I think from an academic standpoint, or cognitive standpoint, I think sensory distractions at times, very, very much so in elementary school but even until this day she can be distracted just by being in a classroom with other people. So sound processing, and how to- knowing which things are important and which things need to be filtered in, filtered out. So, yes, certainly from that standpoint. And then, of course, the social challenges particularly starting in around middle school affected her learning because of just being in school, being worried about other kids and not feeling comfortable in her classrooms. Basically in college- and this might be relevant even with high school- she did not do Virtual School, but I have to wonder sometimes if she had if it would have been a good situation for her. She finds on-line learning a lot less distracting. She doesn't have to worry about a lot of things that she would in a classroom situation.

P1.2 Describe the classes or learning environments where you believe your child was most successful.

And now, are you only talking about high school? (*Clarification- not beyond high school*) Well, from entering... definitely mainstream. I think that having her- she was always completely

P5 Transcribed Responses

mainstreamed; she was never in an ESE class. I think through elementary school- the principal- having an understanding administrator who hand-picked her self-contained classroom teachers to know which ones would be sensitive to her needs. That was important. As she got into the higher grades that option wasn't available, although her guidance counselor, we were very fortunate in high school, did take into account certain teacher personalities when she placed S5 in classes, if there were options available. And so I think... One of the things that I wish had happened with S5 down the road that might have been better for her academically and socially would have been if she would have gotten into either the gifted program or the advanced program somehow. I think she would have been maybe with students- there would have been some students that would have been more helpful and understanding of her differences. So, she's done well with teachers that are very clear in their instructions. She doesn't do- she never did well if there's... the type of teacher that's the kind where they think they're everybody's best friend, I'm Mr. Cool. There's teachers in high school like that, they are basically reliving their high school experience and they try to be too chummy-chummy with the kids and they let things go a lot. S5 needed structure, she needed the rules followed, and again she needed everything explained. Teachers that might sometimes be a little sarcastic, or she wouldn't get things like that. Teachers that let other kids get away with things, or overlook certain things. There are rules, and these are the rules, and this is what you do. So clear expectations were very important to her. Structured learning. Group projects not a good thing. So, those were important and I may have digressed.... I may have gotten off track.

P5 Transcribed Responses

P1.3 Describe the classes or learning environments that were the most challenging for your child.

It would be the group projects and noisy classrooms. Classrooms that involved where- and I know it's in some subjects, there's a lot of stuff, a lot of interaction with kids and a lot of things going on. And maybe I should backtrack. Maybe the gifted program wouldn't have been a good for her because of that, because I know my other daughter was in gifted and a lot of what they did was group kind of things, and kids learning by doing, and that. So anything where there's a lot of noise is not good. Anything where she could get lost in the crowd. S5 was always very well behaved. A teacher's dream. Every teacher said they wished they had a whole class full. But with a teacher that didn't, wasn't aware of what was going on, she could be easily lost. She could look like she could understand, and then not understand. So, I would say anything noisy, where there's kids who are doing what they're not supposed to do would not be a good environment for her.

P1.4 What help – if any – did you provide to your child for home-learning assignments?

Well she had tutors. I mean, that probably. When she was young I would help her study. You know, go through word lists with her and things like that. I'm a math tutor, so I would help her with math, study for that. But as she got older I thought it was important to started backing out of that a little bit. And we, so from about 4th or 5th grade on she pretty much had tutors, from there all through high school for a couple subjects. Usually science and English. Everything else she did quite well with. When she got to college it was really, just very little tutoring at all. She really got a good foundation and she did well.

P5 Transcribed Responses

P1.5 What learning accommodations do you believe were most helpful for your child?

Extra time. Extra time on tests and extra time on sometimes for assignments. Having the pass to go to Mr. Q was a biggie. Just knowing she had it, she rarely used it, but that card saying all she had to do was hold it up to her teacher, and the teacher would just nod and she would go out the door to Mr. Q's room if she was feeling overwhelmed. I think just having it, and knowing she could use it was a huge comfort. I think over the four years she was in high school I think she used it maybe two or three times. Where she actually felt the need to use it. But having it was a big help. Also preferential seating. She could sit at the front. She liked sitting at the front of the class because she then she could- she's not as distracted by what's going on, what the other kids are doing. That was helpful. Being able to, well teachers—she had a 504 plan, she never had an IEP. Those were basically the accommodations that she had. Extended time, preferential seating, and the pass that she could use.

P1.6 During your child's school experience, s/he may have had many different learning experiences. Without naming any specific teacher or teachers, which teacher characteristics (e.g., sense of humor, classroom management skills, instructional methods) do you feel were most effective in helping your child achieve his/her academic goals?

Caring. Someone who she knew understood her, who realized that she was very bright. Even though at times there were things she didn't know that should be obvious. But teachers who understood how bright she really was. And then explain to her very carefully the things that she didn't understand. Those were the teachers that she did very well with, and I give a lot of credit

P5 Transcribed Responses

for her making it to where she's made it, really. You know. I always let them know they should be really proud of what they're doing. Teachers who want to learn about it, because again, you know we're going through a time where- particularly in her elementary years and even into middle school, nobody knew what Asperger's syndrome was. And if you said it was a form of autism, they got scared. That we were fortunate that there were enough teachers that would read about it. I see S5's very bright, but I see she is not like the other kids, and that's not always a bad thing. But you know, they wanted to learn about it, and then do what they could to maybe change things to help her. So the teachers that were going to learn about Asperger's and talk to me as a parent, saying 'Here, this happened, what can I do to – any suggestions of what could be done to help this situation?' Good communication. Yeah.

P1.7 Your child has had many academic experiences throughout his/her years in school. Please tell me about a learning experience that you vividly recall.

Oh boy, the first one that comes to mind, truthfully? I mean, I don't know if you want to go back this far, but it was the second day of Kindergarten. You asked—it's very vivid, and I think it is, I think it really encapsulates what Asperger's is all about. She had- her Kindergarten teacher was hand-picked. Wonderful woman. And S5 went to school the first day, came home, was very happy. The second day I walked her to the class and I said to the teacher 'How did everything go?' and she said 'Oh, S5 is wonderful, but we did have a little problem at lunch time walking to lunch.' And I said, 'Oh, what happened?' She goes, 'Well, I told the kids to line up.' I said, 'S5 didn't get in line?' She said, 'Oh no, S5 got in line.' I said, 'Okay.' And she said, you know, 'I told them we're going to walk to the cafeteria.' And she said 'I kept seeing S5 get out of line.' I

P5 Transcribed Responses

said, 'Oh, then what did you do?' She said, 'I told her to get back in line.' And I said 'What did she do?' And she said 'She got back in the line.' I said, 'Okay, what's the problem?' She says, 'Well, she kept getting out of line, like, the whole time we're walking to the cafeteria.' And I said, 'Oh!' I said, 'How about this. Today why don't you say: S5, we're going to walk in line, you're going to get in line, and we're going to stay in line until we get to the cafeteria and until you get your lunch. Then you can sit down.' She goes, 'Well, that's what I said.' I said, 'Did you say you had to stay in line the whole time?' She goes, 'Well, no, the kids know...' I said 'She doesn't.' I said, 'You're assuming that she knows that's what she meant, but you can't make that assumption.' And she goes, 'Okay.' And when I went to pick her up that afternoon she goes, 'It worked! That was so easy!' I said, well. From then on, that teacher knew exactly what it was. Because she said she always knew, she could tell from the first day S5 was not a defiant child. She knew S5 was going to do whatever I told her to do. But you've got to be very specific about what you tell her to do. And so when you ask what vividly sticks out, that was such an early thing. But truthfully that's something that lingers to today. You can't always assume that just because it's obvious to everybody else, that's it's obvious to her. And, I think teachers that- you know, the ones who understood that, knew that it's never a behavioral issue if she's not doing what they thought they told her to do. It's what she – she's always going to do what she interpreted that you wanted her to do. So, yeah. I would say that.

P1.8 Is there anything else you would like to share about your child's educational experience in school?

P5 Transcribed Responses

We're just talking about public school now? (*Yes*) I think nowadays, hopefully, there's more education to staff and teachers about high functioning autism. And again, when we started this whole journey it really wasn't. And we had to do a lot of the explaining and the educating. And I always felt as a parent I didn't really want to have to be in that role because I think – there's a sensitivity there of feeling like 'You're just saying that because it's your kid' or whatever. And I do think there's so many more kids that are being identified now with having these types of disorders. That there does need to be a lot of education, and peer education, too, is a big thing. Some peer education I think, for S5, and the right- even just one or two kids that would have – and not as a community service project. That's the problem. I think some of it's done with good intentions. But, no, finding other kids where you can say, 'Hey, look. This girl's a wonderful girl. She would be a wonderful friend to anybody. But she's not like your other friends. That doesn't mean...' I think within a large public school, particularly high school, there's got to be a counselor, teacher, somebody that can identify certain types of kids that they know would really be a friend- a real friend. Maybe different experiences than they have with their other friends; but would still be a friend. And I think that would have made a world of difference to this day. Because there's a lot of residual pain and effects of the whole social experience. (*The next section will discuss the social aspects*) So yeah, but I do think that's it's under the whole school umbrella of – I don't know what you want to call it, but something, I think, something needs to be done in there.

P5 Transcribed Responses

Guide Question #P2: What were your child's social experiences as a student with an autism spectrum disorder in the urban public school system?

Subsidiary Questions:

P2.1 Did your child participate in a social skills class? If so, please describe this experience and any changes in your child you may have observed as a result.

In school, no.

P2.2 Did your child participate in any clubs and/or after school activities, including senior events (e.g., Grad Night, Senior Prom, graduation)?

P2.2.2 If your child did participate...

P2.2.2.a In which activities did s/he participate?

Yes. She went to Prom; she went to Grad Night. She was in Best Buddies. And actually, in Best Buddies she was assigned to a lower-functioning autistic kid, so she was like the mentor, which was good in that set. I'm trying to think if she was in other clubs. She was in—yeah, she was in Chorus for a year or two. That wasn't really a club, but it was a class and as a result you had shows and practice and stuff like that.

P2.2.2.b What feelings and/or thoughts did you have as your child participated in these activities?

In, well, with the Grad Night—Grad Night in particular I was nervous. I knew that she already—there were a couple girls that she knew that seemed nice that she was going to hang with. Prom, she went with another young man who has Aspergers who is a few years older than her. She had gone to his prom with him when he graduated. I wasn't really concerned about that. Best

P5 Transcribed Responses

Buddies I thought was fine. A little concerned, I guess, about the Chorus, whether she'd be accepted in there. I guess it was always a matter of how she was going to be okay with the other kids.

P2.3 What help did school personnel provide, if any, for your child's participation in social activities?

P2.3.1 Describe any help that your child received.

Well, Mr. Q, who was the autism teacher at her high school, he usually went on some of these things because he might have a student of two that was going. I mean, I guess that was about it.

P2.3.2 Was this help effective? Why or why not?

Oh yes, wonderful.

P2.4 Tell me about the friends your child had in school.

P2.4.1 Was it easy or difficult for your child to make friends? Please explain.

Difficult. (*Probe*) Elementary school, I think she was oblivious to it. She was very happy. Everything was fine until middle school. Middle school is challenging for a lot of kids, but she was like wronged. And I girls- I think it's even worse. You don't have to have a disability or, in this case a hidden disability, to be ostracized by your peers in middle school. Add to that the naïveté. One of the things that happened with S5 that I noticed a lot is- and you noticed this- and I'm not just saying this as her mom, but God bless her, she's a very pretty girl, very sweet. And so she does attract people – people come over to her and make friendly overtures. Depending on how she feels about that person she might just become – initial she might have

P5 Transcribed Responses

nice conversations. But what would happen after a while, they would, you know- and in middle school this was a problem- decide that maybe she's a little different. Or she's always talking about the same things. And then they want to be gone, but she's decided they're her friend. And it took her a long time to differentiate between who's a friend and who's a – just an acquaintance. And who is trying to set you up and deceive you, and all that. So that's been one of the things that I think she's gotten through quite a bit. Yeah, it was hard for her to make friends.

P2.4.2 How would you classify most of your child's friends: students with ASD or neurotypicals (without ASD)?

In the past? Through the school, most of them had an autism spectrum disorder and they even live nearby. They were- she was in social groups outside school. And she did make some nice friends. But then as everybody kind of graduated and went off to school, there was a lot of distance, a lot of differences. She has made some friends that are quite a bit older than she is. But, they are friends; they are people who care about her. And she can go to and they don't have an autism spectrum disorder, but there's very few.

P2.5 Would you characterize your child's social experiences in school as mostly positive or mostly negative? Please explain your response.

Negative. (*Probe*) Concerned about her social naïveté and people taking advantage of her.

P2.6 Is there a social experience your child had in school that you vividly recall? If so, please describe what you recall.

P5 Transcribed Responses

There's so many of them. Again, are we only talking about public school? Because for middle school she went to private school, and that was the worst. (Q?) Because she was set up with a young lady that was her friend for a while – for about six weeks, no, maybe about three months they were inseparable, together all the time. And then the other girl just turned on her with a bunch of other girls. The girl was the daughter of the principal. And it was a just horrible. I should have pulled her out of there.

P2.7 Is there anything else you would like to say about your child's social experiences in school?

Right from 5th grade it started- where girls started, like tricking her; being mean to her; taking advantage of her naïveté. She got sent home in 5th grade, supposedly with lice. Which she didn't have. Because some girls went up to her during lunch and said,, 'Oh, your hair is so pretty.' They had applesauce on their fingers, and they said, 'Oh, your hair is so pretty' and they were touching her hair. And then when she got back to class, they started going, 'Ew, look, S5 has lice, S5 has lice!' And they called me and they sent her home. And they said I had to come get her because they suspected she might have lice. And because there was dried up applesauce in her hair they sent her home. And she didn't have lice, she just had applesauce in her hair. And she remembers that. And of course the girls just thought it was so funny, the coolest thing to do. Yeah, so that was when it started. Up until then, up until about 5th grade the kids kind of were, they were okay. She did get made fun of for not being able to kick a ball in 4th grade. But our neighbor, he was determined he was going to teach her how to do it. You know, they grew up together. He was going to teach her how to kick that ball. And he almost beat up the other kids.

P5 Transcribed Responses

She had a hero. But yeah, kids who are – it's one of those things that I've always explained to her through the years, kids can be mean whether you have a disability or not. They could be mean. And so the problem, I guess, that you're having most of the time is that you don't always realize it when they're being mean. I said I don't think they're being mean- she said 'Because of my Asperger's?' I said I don't think they're being mean because your Asperger's. They can be mean because they don't like the color of your hair or because you have freckles, or you have glasses. I said it's that, in your case, you're not always realizing they're being mean. They're acting friendly and then they're—so that was usually the pattern that would happen with her. And, you know, it's definitely had residual affects to this day. She doesn't trust people. It's easier to do the on-line courses; it's easier just to decide she's not going to meet people. That she's fine alone. Just meet people, she's okay. Because she doesn't have a lot of friends because I think it's easier to just trust herself and trust her family and a few family friends than it is to try to trust new people you meet. And that's where a lot of the therapy comes in, and everything else. But when you still are in a situation where, you know, you look at this beautiful, bright girl who doesn't go out—doesn't do anything. Doesn't have one person she can call up and say 'Hey, let's go hang out. Want to watch a movie? Want to do this?' So. I think it bothers me more than it bothers her. She'll say it doesn't bother her, and maybe by now it doesn't. It bothers her because it's what she thinks I want. I want her to be happy.

Guide Question #P3: What do you remember about your involvement and your child's involvement in his/her school experience?

P5 Transcribed Responses

Subsidiary Questions:

P3.1 Did you participate in your child's individual education plan (IEP) meetings?

504 meetings, oh yes.

P3.1.1 If you participated please describe your experience in these meetings.

In high school, going into high school it was good, very, very good. She had, I said earlier she didn't have an IEP, but I take it back. She had one in her early childhood. It was dropped after first grade. The principal didn't think it wasn't necessary for her to have anything any more, which was fine. But it was very difficult staffing her going into Pre-K, as I mentioned earlier. The person in charge of staffing for the county was insistent that she be at a minimum in a VE adamant that I wanted her mainstreamed, and I wanted her mainstreamed at the XX Preschool laboratory in particular. The woman made a remark at the meeting that I thought was very inappropriate. Which was this—and I don't think any professional should ever say this: 'Well, if it were my child, I would put her in a VE class or an autism class.' And all I can say is, with my daughter graduating from college tomorrow, good thing it wasn't! And I thought about, if she's still with the county, sending her S5's graduation announcement. She probably wouldn't even know who she was. I mean, I think for S5, mainstream was the right thing. I really do. Because we took care of some of the other things through insurance, and a lot of it we paid for ourselves. But I think that some of the things can – you can get all these services without having to be in a self-contained ESE class. You can get – if you need- therapy, you can get all those things.

P3.1.2 Did your child participate in his/her IEP meetings?

Yes, she did.

P5 Transcribed Responses

P3.2 Was there a time when you requested an academic experience and/or learning accommodation in which your child did not agree?

That I requested an academic experience or learning accommodation? (*Clarification*) She would say that she didn't want to do drama, and we had her in drama class. But at the time, she agreed with it. It's now in hindsight where sometimes she'll say, 'I didn't want to do drama, you made me do drama.' And I said, 'Well, no. Nobody made you do drama. The staff, during the staffing, suggested the drama might be a good social outlet for you. It was just a suggestion and you were fine with it.' If she had ever said 'I don't want to do that', she wouldn't have done it. I don't really think—in her mind there might be, but at the time there were no problems.

P3.3 **Do you remember a time when you wanted something for your child's school social experience in which your child did not agree?**

We're talking school related? I think while she was in school she was very open to things that might lead her to have more social experiences. I always wanted her to be comfortable with them, so I wasn't going to say something like 'Go run for office'. Or, you should join this club, or you should join that club. Usually the teachers or the counselors would maybe make suggestions to her. There probably is something along the way, but we try. Oh, there were some social groups outside of school that she tried, but didn't go well. And when she didn't like it, that was the end of it. She wasn't forced to do it.

P3.4 **Did you participate in meetings for your child's transition into post-secondary school educational or vocational opportunities?**

There were no meetings because of the 504.

P5 Transcribed Responses

P3.5 Is there anything else you would like to tell me about your involvement in your **child's** academic and social experiences in public school?

In the school system it was very good to have a 'go to' person. Not just for her, but for me, as well, that understood the Aspergers. And so in our case it was Mr. Q. If there was an issue going on, whether it be academic, social, anything that I got wind of, I could e-mail him or call him and he was always very open. And then he would right away check into it and find out what was going on. Sometimes he could speak to a teacher, and, you know, how to nip something in the bud. That was always his feeling: nip it in the bud. And that was just very good—don't let it get to where it escalates and becomes a big thing. And so he was always helpful. I think as a parent - that was very valuable to me to know there was one person I could contact that would then do the thing they needed to do. I never had to call the principal, never had to go to any – just he handled it. It was dealt with in the right way. And I knew he'd always deal with it the right way. So I think having a person in the school that's understands it- can be a liaison between the child and the parent and the rest of the staff. I think that's important.

APPENDIX K
STUDENT INTERVIEW SUMMARIES

S1 Summary

Guide Question #1: What was your educational experience as a student in a large urban public high school?

In general, S1 felt academically unsuccessful. Social experiences in classrooms presented a challenge, as well as classes that were either too easy or uninteresting. S1 mentioned specifically that he hated school because of all the people judging him. S1 preferred teachers who understood why, at times, he could not do the work. Memories of academic experiences, S1 reported, have been repressed. S1's mother assisted with home learning assignments, but S1 did not recall how she assisted.

Guide Question #2: What was your social experience as a student in a large urban public high school?

S1 reported that his social experiences were very negative, and there was no support provided from school personnel to help him. S1 did not participate in social activities of events, except for graduation, which was "nerve-wracking and sweaty." S1 indicated that he knew in theory how to make friends, but found the practice of doing so very intimidating. S1 stated that he would have liked to be in a social skills class.

Guide Question #3: What do **you remember about your involvement and your parent(s)' involvement** in your school experience?

S1 had a neutral feeling about his IEP meetings. S1 recognized that his parents wished he had been more social. S1 felt that others over-estimated his ability to be social because he was so

intelligent. S1 believed public high school did very little to prepare him for college because grade school and college are so different.

Field Notes During Interview:

S1 arrived to the interview with his mother. He was wearing a hoodie-type sweatshirt with the hood over his for the majority of the interview. At times, he would lower the hood to cover his eyes. S1 made limited eye contact during the interview. Responses to questions were concise, with little elaboration provided. On occasion the interviewer had to probe to get a complete response to the question. There were lengthy pauses before S1 responded to the questions, and he spoke slowly and carefully. S1 let out a sigh, presumably of relief, when he was told the interview was over, and he got up quickly from the table.

S2 Summary

Guide Question #1: What was your educational experience as a student in a large urban public high school?

S2 needed academic assignments, especially those that were project-type assignments, to be explained explicitly, step-by-step, otherwise he missed an important part of the process. He preferred the assignments that were not project based. S2 had difficulty with math: he understood the formula but had difficulty applying the data to make the formula work correctly. S2's parents assisted with home-learning assignments by explaining what was written in the texts. Extended time on assignments and tests was a necessary accommodation for S2, and the teacher characteristic that was most helpful to him was patience because he would have to have things explained several times. S2 had difficulty in auditorium classes, especially if the room was dark and a movie was showing, because he would fall asleep. This was embarrassing to S2. Overall, S2 felt his high school academic experience went rather well.

Guide Question #2: What was your social experience as a student in a large urban public high school?

S2 did not participate in a social skills class, and attended only graduation as a social activity in high school. S2 stated that he's not good with large crowds, loud shows, and parties. Even in family gatherings, S2 does not speak to others until spoken to. No assistance was provided by school personnel to assist with social skills. It was more difficult for S2 to make friends in elementary school than in high school, and the friends he did make in high school had similar interests (art, computer animation). S2 assumed those friends

did not have an autism spectrum disorder. S2 stated that high school was a neutral social experience, while elementary was a negative experience. S2 recalled a time when he and others in his art academy played a joke on the photography magnet students. The only students S2 talked with were those in his Arts magnet.

Guide Question #3: What do you remember about your involvement and your parent(s)' involvement in your school experience?

S2 and his parents participated in his IEP meetings, but S2 didn't like being the center of attention. He mentioned having a feeling like he had done something wrong and was sent to the principal's office. S2 did not agree that he should have the meetings at all, although he admitted that some of the things that were discussed were helpful to him. S2 mentioned that his parents asked him if he wanted to participate in social activities, but S2 said he didn't do proms and that sort of thing. S2 recalled a group transition meeting, but no individual transition meeting. Altogether, S2 felt that high school did a pretty bad job of preparing him for post-secondary experiences (Full Sail college) because high school did not teach him the prerequisite skills needed for full participation in the computer animation college.

Field Notes:

S2 met with the interviewer at a table in the dining room of the family's house. He was cleanly dressed, but wore no shoes. It appeared he was unshaven for a period of days. S2 made eye contact with the interviewer; however, his gaze was prolonged at many times during the interview, making such eye contact uncomfortable. Many times during the interview S2 would snort, and it was not determined whether this was a nervous twitch, part of a sensory discomfort of too much mucous, or if this was part of A2's ritualistic or idiosyncratic characteristics.

S3 Summary

Guide Question #1: What was your educational experience as a student in a large urban public high school?

Working with other students on class projects and concentrating on tasks were difficult areas for S3 in the school. S3 believed that over time he learned how to function in “less than ideal” learning environments. S3 preferred classes where he had an opportunity to express his talents in his area of interest, writing. Sharing his writing talent helped other students get to know S3 better, which made S3 happy. S3 was a well-behaved student, and classes that had a feeling of restrictiveness made S3 feel “nervous and apprehensive.” S3’s parents were unable to assist with his home-learning assignments because of the high level of his academic work. S3 felt that extended time was helpful so he was able to focus and concentrate (although later in the interview he stated that he did not like to use extended time because it made him feel inferior to other students). Teachers who displayed encouragement, understanding, and empathy were helpful to S3’s academic success. In retrospect, S3 stated that while he received a good academic education in high school, there is a part of high school that he didn’t take advantage of: the social experience of football games, pep-rallies, and fooling around with friends. He wished he had done more of that and worried less about his academic work.

Guide Question #2: What was your social experience as a student in a large urban public high school?

S3 did not participate in a social skills class in school. S3 liked to help others, and he mostly socialized with people who were also helping others. While S3 participated in many clubs and honor societies, he reported a feeling of detachment from others in the groups. S3

mentioned that he would have liked to hang around with the others in the group because he thought they were “cool,” he just didn’t know how to do it. The special education program specialist and department chair provided some guidance to S3’s participation in social activities, and also helped him in other social situations that were confusing to S3. Because S3 was in Honors and AP level classes most of the students he was with in class were ambitious and hard working, but S3 felt detached from them as if they were on a level he couldn’t reach. Most of the students that S3 did socialize with were “misfits and unpopular,” but they welcomed S3 into their group. S3 couldn’t say whether these students were with ASD, but they were “weird, an eccentric bunch.” S3’s high school social experience got off to a rough start, but it improved somewhat in 11th and 12th grade. When asked of a social experience that he vividly recalled, S3 stated that psychologists say the negative or traumatic experiences are the most vivid. Therefore, S3 recalled that PE was the most vivid because he was always picked on, or chosen last to be on teams. In closing about social experiences, S3 said that the best relationships he developed in high school were those he made with teachers, and those relationships “endure to this day.” As far as the rest of his high school experience, S3 stated that he wanted to move on with the rest of his life and look forward to better experiences.

Guide Question #3: What do you remember about your involvement and your parent(s)’ involvement in your school experience?

S3 and his parents participated in his IEP meetings, and S3 found them to be comfortable and helpful. While extended time was an accommodation that was recommended for S3, he didn’t really want to use it because he didn’t want to feel “inferior to other students.” S3 also recalled that his parents wished for him to have more friends in school; S3 didn’t see the need for

those friendships at the time. S3 and his parents participated in Transition meetings, and continue to meet regularly with counselors from the office of Vocational Rehabilitation. While high school taught S3 about a lot of things, he didn't believe that high school really prepared him for what happens in the real world. S3's final statement was that his parents were always there for him, providing their dedication and support. S3 believed that parental encouragement is what all students need to be successful.

Field Notes During Interview:

S3 arrived at the interview location with his mother. S3 was very polite during the interview, and spoke very respectfully of teachers and his parents. S3 appeared comfortable in the interview environment, and had no difficulty making eye contact with the examiner. S3's speech lacked fluidity as he repeated words and multiple-word phrases. He was very formal in his discourse, and attempted to be precise and thorough in his responses.

S4 Summary

Guide Question #1: What was your educational experience as a student in a large urban public high school?

S4 believed that he has the same capacity to learn as any other student, and in fact may be able to pay attention better than others. S4 felt most successful in classes that weren't too loud, however S4 believed he could adapt to any kind of class. Math was S4's most challenging subject, and parents provided a tutor for him for math and sometimes for science. S4 stated that he preferred sitting in front of the class, although he didn't think it was a specific accommodation on his IEP. S4 recalled that one of his teachers had a sense of humor, and this made it easier for him to understand the subject matter. S4 enjoyed making a Senior Memory book in his English class, and still has this book in his room. Overall, S4 said his educational experience was great.

Guide Question #2: What was your social experience as a student in a large urban public high school?

S4 did not take a social skills class, and preferred that others not know that he has autism. He participated in several school clubs in his magnet high school (S4 was enrolled in the Agri-Science magnet) as well as all the senior events. S4 told the interviewer he "especially participated in graduation because if I didn't participate in graduation I wouldn't be here right now." S4 was satisfied with his level of participation in school related activities, and he had friends- but not a best friend. School personnel did not provide support for S4's participation in social events, and it wasn't until his junior year that S4 decided to "step forth and try to make

friends.” S4 said that his social experience was mostly positive, and he tried to focus on his education and make sure his friends were not “shady.” S4 later recalled that he had a best friend in elementary school, and maintains contact with this friend through FaceBook. Overall, S4 believed that for a student with ASD he did well socially.

Guide Question #3: What do you remember about your involvement and your parent(s)’ involvement in your school experience?

S4 states that he and his parents participated in his IEP meetings, and he felt comfortable. Extended time was an accommodation that was requested for S4, but he doesn’t feel he really needs it. Socially, S4 stated that he and his parents wanted him to have a normal social life. S4 vaguely recalls the Transition meeting and that his parents attended. He believes that his magnet high school prepared him very well for post-secondary educational opportunities. At the conclusion of the interview, S4 stated that he was like most teenagers and didn’t want his parents “on top of me for everything.

Field Notes During Interview:

S4 was interviewed at a location outside a public library. S4 responded to all questions, and appeared at ease with the interviewer. There were times that questions had to be clarified, and even times when S4 contradicted himself. He did not become upset nor flustered, but remained calm throughout the interview process. S4’s speech was slightly pedantic. S4 was very neatly dressed, and he wore glasses that were photosensitive and darkened in the outdoor location.

S5 Summary

Guide Question #1: What was your educational experience as a student in a large urban public high school?

Having an autism spectrum disorder affected S5's ability to handle abstract thought, and also to do art because of fine-motor problems. S5 reported that her handwriting is terrible and she is very uncoordinated. S5 felt successful in learning environments that were highly structured and where teachers explained things clearly. Classes where she got low grades affected S5's self-esteem. S5 had difficulty with Geometry because of having to draw constructions. The most difficult subjects were a combination of math and science. S5's parents provided a tutor for her throughout most of middle school and high school. S5 says that she is pretty organized and did not need help with that. Extended time for tests and assignments was an important learning accommodation. Teacher characteristics that S5 did well with were those who were structured, organized, and very detailed. S5 recalled a teacher who gave her a bad grade on an assignment because S5 was uncomfortable giving oral presentations (S5's report was on autism). S5 believed that most teachers didn't really understand the way she learned, which was mostly visual. S5 said that she wasn't outstanding academically, she didn't excel in any subject, and she didn't really push herself to do better.

Guide Question #2: What was your social experience as a student in a large urban public high school?

S5 began this set of questions saying that this was going to be hard, and she didn't want the interviewer to judge her for her answers. S5 indicated that she did not participate in a social

skills class. She participated in very few high school social activities: Senior Prom, Grad Night, Graduation, and chorus. Even though she did those events, S5 reported feeling as if she were a passive observer. She believed that others exhibited more confidence, and at times were almost too self-confident to the point of annoyance. School personnel provided no assistance to S5 for her participation in school social experiences. It was very difficult for S5 to make friends; she was a loner. S5 stated that she has friends with Asperger's, but the friends she has at school do not have Asperger's. In fact, S5 shares that she doesn't have many friends right now due to her autism spectrum disability. S5 stated that she tried to be part of an Asperger's support group, but it was mostly boys and she doesn't feel comfortable around boys. S5 characterized her social experiences in school as neutral, mostly because she had so few experiences. She stated that too many social stimuli made her anxious. Other than being teased by others, S5 could not recall a social experience to talk about. S5 concluded this section of questions by saying that she hoped the interviewer didn't think negatively of her.

Guide Question #3: What do you remember about your involvement and your parent(s)' involvement in your school experience?

S5 stated that she and her parents participated in the meetings about her 504 Plan. She recalled that her parents would try to get her involved in things that she wasn't interested in, like drama class, and S5 would usually at least try. S5 reported that she believed her parents were frustrated with her because she didn't have many friends, but S5 felt comfortable by herself. S5 stated that, unlike most people with Asperger's, she worries about what people think of her and she tries please others. There was not a Transition meeting for S5 due to the 504 Plan (not an IEP), and S5 decided on the college herself. S5 recalled assistance she received in the form of a

“go to pass” to see the ASD teacher. While she wasn’t in his class, this teacher was available to S5 if she had any concerns, and she found that very helpful.

Field Notes During Interview:

S5 was interviewed in her home, in a study area that her mother uses for tutoring. Both S5 and the interviewer were wearing the exact same turquoise blue sweater (which was more than a few years old), and rapport was quickly established as S5 and the interviewer discussed other things they had in common. During the interview itself, S5 twisted her hair while responding. She also kept expressing concern that the interviewer would judge her less than favorably upon hearing her truthful responses. S5 had an expressive voice, and she made good eye contact throughout the interview as she responded to all of the questions asked.

APPENDIX L
PARENT INTERVIEW SUMMARIES

P1 Summary

Guide Question #1: What was your experience as the parent of a student with an autism spectrum disorder in a large urban public high school, in meeting your child's academic needs?

Son's academic success was limited by his social challenges, and if he got upset, he would "shut down" and not want to return to school. An environment where S1 felt accepted by others helped his possibility of success, as well as classes that were in his area of interest. S1 didn't put forth effort for sustained periods of time in the academic areas he didn't excel in (math). Care and encouragement by the teacher were helpful characteristics for S1. P1 felt the school should have done a better job of communicating with her, especially since S1 didn't provide much information to her on his own. P1 provided guidance to home learning assignments, but not actual assistance with learning the subject.

Guide Question #2: What was your child's social as a student with an autism spectrum disorder in a large urban public high school?

P1's son was diagnosed late (11th grade) so he did not get a social skills class in his school schedule. P1 expressed frustration that professionals didn't recognize S1's anxiety and depression as related to Asperger's until he was so depressed he had to be hospitalized. Social situations scared him, so he had no social experiences. No assistance by school personnel was provided to assist with social situations, except for the graduation ceremony. Making friends was always very difficult, especially after elementary school. P1 reports that others picked on S1, but S1 also shut mom out and didn't share much information with her.

Guide Question #3: What do you remember about your involvement and your child's involvement in his/her school experience?

IEP meetings were a positive experience because of the ability to have time to communicate with S1's teachers. At least one parent always attended, and S1 attended rarely. Transition meetings didn't encourage S1's enrollment in college, the discussion was more geared to a vocational post-secondary setting, and that bothered P1. P1 sees college as much different from high school, and believed that high school did not prepare S1 well for the college experience. P1 believed that teachers need more awareness of the needs of students with Asperger's so they are better able to help those students.

Field Notes During Interview:

S1's mother participated in this interview. She was neatly dressed and very open to sharing her experience with the interviewer. Rapport was easily established as P1 and the interviewer had mutual acquaintances to discuss prior to the interview. P1 answered all questions without hesitation, and provided enough detail to help give a clear understanding of her perspective of S1's and her experience in a large urban public high school.

P2 Summary

Guide Question #1: What was your experience as the parent of a student with an autism spectrum disorder in a large urban public high school, in meeting your child's academic needs?

P2 stated that children with autism spectrum disorder have two main challenges: their ability to organize information that is needed to do tests and homework; and their ability to understand the social aspect of learning, including communicating with peers and understanding body language. P2 felt that learning environments where their son was successful were those that had small numbers of students and teachers who understood learning differences. Classes that were considered fun and interesting to their son were also positive environments. Large auditorium type class environments were very difficult for their son. For home learning, S2's mother provided organization for S2, including color-coding his binders. Organization is S2's main challenge. The Internet sites, where parents can access class information from the teachers directly, would have been very helpful to P2 and his parents. Teachers who were fun, organized, and had a sense of humor were those who were effective in their efforts with S2. There was an unfortunate occurrence during middle school, when S2 was in a private school, where S2 was targeted and bullied. Public high school was a much more positive experience for S2.

Guide Question #2: What was your child's social as a student with an autism spectrum disorder in a large urban public high school?

S2 did not participate in a social skills class in public school, nor did he participate in any clubs or school activities. School personnel provided no assistance in facilitating S2's

participation in school social activities. Although P2 asked if S2 wanted to do something social, S2 indicated he would rather not. It was always extremely difficult for S2 to make friends, and P2 believes this was due to S2's inability to communicate with peers and understand them. The few friends S2 had were those with common interest in the arts and in video games. P2 stated that S2's social experience in school was neither positive nor negative: it was non-existent. Although there was a love-interest in high school, the relationship didn't work out. P2 wishes that S2 had had more social experiences.

Guide Question #3: What do you remember about your involvement and your child's involvement in his/her school experience?

P2 always participated in S2's IEP meetings, and while they found them to be very helpful because many recommendations were discussed, the recommendations didn't come to fruition. S2 also participated in the meetings. P2 recalls requesting that S2 have an accommodation of a note-taking buddy in the classroom. It apparently didn't happen because S2 didn't want to be singled out in the class. Regarding social experiences, P2 really wanted more experiences for S2, and even tried to enroll him in social groups through local agencies, but S2 never wanted to participate. Although they participated in a Transition meeting, P2 believes that S2 was not well prepared for college at all; in fact he was "completely lost." P2 wishes, in retrospect, that S2 had attended a local community college before going to an out-of-town college specializing in visual arts.

Field Notes During Interview:

This interview was conducted in the family home. Both parents participated in the interview, however the father was much more vocal about his son's experiences. Mother agreed

with all that was stated by father, and added some of her own observations. Rapport was easily established, and the parents answered all questions openly and without hesitation.

P3 Summary

Guide Question #1: What was your experience as the parent of a student with an autism spectrum disorder in a large urban public high school, in meeting your child's academic needs?

P3 stated that her son's biggest challenge in school was his ability to learn in social environments; he preferred to work by himself in a quiet room. Group projects were especially challenging because S3 believed he could do a better job on the project than the other students, so would want to do the work on his own. P3 did not help S3 with his homework, but did provide support through time management and making sure he completed assignments on time. Extended time on tests and assignments, as well as preferential seating, were necessary learning accommodations, although P3 acknowledged that S3 rarely wanted to use any accommodation. Teacher characteristics that were helpful included a sense of humor and a relaxed, laid-back style of teaching that made S3 feel more comfortable in the class. P3 recalled a learning experience where S3 learned a Shakespearean soliloquy, and performed it in costume in front of the class. As a result of this performance, S3 got high praise from his peers, and some encouraged him to enroll in drama.

Guide Question #2: What was your child's social as a student with an autism spectrum disorder in a large urban public high school?

S3 did not participate in a social skills class in school. P3 encouraged S3 to do social activities. At first he didn't want to, but eventually he joined some clubs and honor societies at school. With P3's encouragement, S3 participated in a few community experience activities at

school. It was difficult for S3 to make friends, especially in 9th and 10th grade, and P3 believed the friends S3 did have did not have an autism spectrum disorder. P3 recalled a social experience when a girl whom S3 didn't know kissed him. S3 made an emergency call to P3, who was at work, because he was confused by the experience. When P3 explained that it wasn't love that made the girl kiss him, but hormones, S3 got upset and threw away the shirt he was wearing because he believed that the shirt was what made him attractive to the girl. While S3's first kiss experience was "yucky," P3 thought that, overall, S3's school social experience was a positive one. P3 stated that she wished there had been a social skills class available for S3 in the beginning of high school.

Guide Question #3: What do you remember about your involvement and your child's involvement in his/her school experience?

P3 and S3 attended every IEP meeting, and found them to be very helpful. The Transition meeting at the end of high school was very good. Suggestions were made in the Transition meeting that P3 thought were very positive, including the suggestion that S3 live in the dormitory even though the university S3 was attending was not too far from the P3 house. Since the Transition meeting, S3 and P3 maintain communication with the Vocational Rehabilitation counselor. P3 did wish S3 had more social experiences, specifically going to Prom. S3 did not feel a need to go to Prom, and so didn't. P3 stated that orienting S3 to new school environments- such as the with the transition from elementary to middle school or middle school to high school- was helpful so S3 could check out where the classes were located and figure out how long it took to get from one location to another. P3 believed that S3's school experience prepared him very well for the university. P3 mentioned that close communication

between P3 and school was very important to S3's success in high school. P3 acknowledged that S3 was very successful academically, but needed a lot of encouragement socially; P3 reiterated that encouragement was the most important thing.

Field Notes During Interview:

P3 spoke very openly about her son's experience in school, and answered all questions without hesitation. She is of Asian descent, and at times had difficulty finding the correct words to convey her ideas. P3 was very polite before, during, and after the interview. Eye contact with the interviewer was somewhat limited, but this could be due to cultural factors.

P4 Summary

Guide Question #1: What was your experience as the parent of a student with an autism spectrum disorder in a large urban public high school, in meeting your child's academic needs?

P4 indicated that their response to this question depended on the environment or level (elementary, middle school, high school), and believed it was important for a study such as this to start from the beginning. S4's elementary school was excellent. For middle school, for a few months, he went to a private school and had a terrible experience. He then transferred to a public middle school, and a few weeks later a fellow student was killed in one of the bathrooms. S4's high school experience was excellent. P4 stated that having ASD did not affect S4's ability to learn; to the contrary S4's memory was more developed than other kids'. Math and history classes were those where S4 had the greatest success. Middle school was particularly challenging for S4; P4 found that students in middle school could be cruel, especially to people with disabilities. P4 provided support and structure for home learning assignments. S4's older sister helped tremendously in P4's success in school. Sister was unaware of S4's ASD diagnosis until she was in high school, and as such his sister and other family members treated S4 like any other child, even though S4 was diagnosed with ASD at the age of three years. P4 reported that S4 had very good teachers in high school who loved him and guided him. S4 got into the magnet high school because of his love for animals, and his interest in the Discovery channel. P4 summarized that transitions from one level to another (elementary to middle school, middle school to high school) were challenging experiences.

Guide Question #2: What was your child's social as a student with an autism spectrum disorder in a large urban public high school?

S4 did not participate in a social skills class. He did participate in school clubs and activities, and held an official position with one of the clubs. P4 reported that S4 told his parents to leave, that he didn't want his parents to be around the social events. P4 were happy about this, but also concerned about what his social involvement was going to be like. S4's Agri-Science magnet teacher encouraged him to participate in related clubs and activities, and P4 believed that was helpful. It was very, very difficult for S4 to make friends, but somewhat easier with the girls than the boys. S4 had many acquaintances in high school, but he never introduced them as friends to his family. Most of the people S4 knew were without ASD. P4 shared that they just didn't know about S4's social experiences, so it was difficult to classify them as positive or negative: it was an unknown. S4 still has a friendship with a boy from elementary school, and they still talk and text. The friend has high functioning autism and currently attends a university 400 miles away. Overall, P4 stated that S4 is very independent, and is very good with the teachers, all his teachers loved him.

Guide Question #3: What do you remember about your involvement and your child's involvement in his/her school experience?

P4 always participated in S4's IEP meetings, and S4 participated once he was in high school. The meetings were excellent because they brought up all the things he needed help with. Extended time was an accommodation that was listed on S4's IEP, but he never used it because he didn't want to be different from the other students. S4 and P4 participated in Transition meetings and found them helpful to see options that were available to S4 after high school. P4

believed that high school did a good, but not excellent, job in preparing S4 for college or university. This was mostly because college and university are so different from high school. P4 wished that there were high school experiences that would replicate the college experience, since it would take so long for S4 to adapt to new experiences. Overall, P4 believed it is very, very important for parents to be involved with their children. After receiving the diagnosis of ASD for S4, P4 researched and found out about a seminar being presented by Temple Grandin. P4 attended the seminar and found the experience to be inspirational. P4 reiterated how important it is for parents to be involved in their children's lives.

Field Notes During Interview:

Both mother and father arrived for this interview, along with S4's older sister. It was evident that this family is a warm and supportive family unit. Rapport was easily established. Father did most of the speaking, and mother agreed with all that the father said. Mother shared about finding out about Temple Grandin, and sharing Temple's story with her husband. The older sister was most involved with S4's social experience and indicated that S4 wanted to be independent of her. The parents answered all the questions completely, but were cautious at the end of the interview to be sure that they would receive a copy of this study once it is completed.

P5 Summary

Guide Question #1: What was your experience as the parent of a student with an autism spectrum disorder in a large urban public high school, in meeting your child's academic needs?

P5 believes having an autism spectrum disorder (ASD) affected S5's ability to learn because of sensory distractions and social challenges. S5 would be worried about being around other kids and didn't feel comfortable in the classroom. S5 finds on-line learning much less distracting; she doesn't have to worry about a lot of the things she worried about in a regular classroom. Being in a mainstream setting with hand-selected teachers, whenever possible, was helpful to S5's success in school. S5 also did well with teachers who were clear in their instruction and in their classroom discipline and relationships with the students. S5 had difficulty when teachers used sarcasm. She also had difficulty with noisy classrooms and group projects. P5 provided tutors for S5 throughout high school, usually for science and English. Extended time for tests and assignments was a helpful learning accommodation, as well as preferential seating, and having a pass to see the autism support teacher when she felt overwhelmed. P5 believed that S5 did best with teachers who were caring, and recognized how bright S5 was, and who took the time to understand more about Asperger's. P5 also believed that good communication was an important element. P5 recalled a learning experience that went back to S5's second day of Kindergarten. S5 did not understand the rules for walking in line to the cafeteria. When P5 explained that the teacher had to tell S5 all the steps involved, including staying in line until she reached the cafeteria, that S5 would follow the rules and be successful.

When the teacher did that, S5 was able to follow the expected rules of walking in line. The lesson learned in that was that the teacher can't always assume that just because a rule is obvious to everyone else that it is obvious to S5. S5 never willfully disobeyed, she just did what she interpreted the teacher wanted her to do, and that wasn't always correct. P5 wished there had been a peer-education or buddy type program for S5 that would have provided support and friendship for S5.

Guide Question #2: What was your child's social as a student with an autism spectrum disorder in a large urban public high school?

P5 stated that S5 did not have a social skills class in high school. S5 participated in Prom and Grad Night; she was also in Best Buddies, and was a buddy to a lower-functioning student with autism. P5 mentions feeling nervous about S5's participation, particularly with Grad Night. S5 also participated in chorus, and P5 was concerned whether S5 would be accepted by the group. The autism support teacher provided social support for the lower-functioning students with autism, and was also available to S5 if she needed help. It was always very difficult for S5 to make friends. During elementary school, P5 believes S5 was oblivious to the fact that she didn't have friends. In middle school peer relationships got worse, especially with the girls. Because S5 is so pretty, she attracts attention from others, but doesn't always know how to respond to the friendly overtures. Most of the people that P5 considers S5's friends have an autism spectrum disorder. P5 believes most of S5's social experiences in school were negative, due to her social naïveté and people taking advantage of her. P5 recalls a girl in middle school who made friends with S5. A few weeks later, the other girl turned on S5 and started ridiculing her in front of others. Girls, especially, were mean to S5. P5 recalls a time when girls had

applesauce on their fingers, and felt S5's hair saying how pretty it was. Later, the same girls pointed to S5's hair and said she had lice (dried applesauce) and S5 was sent home. S5 didn't always recognize the pattern of girls being friendly and then being mean, and as a result S5 doesn't trust people. P5 thinks it bothers her more than it bothers S5, but S5 is a pretty girl, but doesn't go out, doesn't do anything, doesn't have a friend to hang out with or watch a movie with. S5 says it doesn't bother her, but P5 only wants her to be happy.

Guide Question #3: What do you remember about your involvement and your child's involvement in his/her school experience?

P5 attended all meetings for S5, IEP meetings in early elementary school and 504 Plan meetings after that. P5 credits the fact that S5 is graduating from college to P5's insistence that S5 be in fully mainstreamed settings with accommodations. P5 provided other services, therapies and social groups, outside the school setting. Regarding any learning accommodations, the suggestion was made at a staffing that a drama class would be a good social outlet for S5. She originally agreed to it, but later S5 said she was made to do drama. Usually she was open to trying things, but if she really didn't want to do something, P5 would not have insisted. S5 tried some social groups for students with Asperger's, but they didn't go well, so P5 discontinued that. There were no Transition meetings. P5 felt that having a 'go to' person was very important for any issue, whether academic or social. It was helpful for P5 as well as S5 because this identified person was able to deal with problem areas immediately, and acted as a liaison between P5 and the school staff.

Field Notes During Interview:

This interview was conducted in the home of the subjects. The mother participated in the interview; the father was on his way to the grocery store. There were several animals in the house, including a few dogs and talking birds. In fact, P5 had one bird in her front pocket and on her shoulder during most of the interview. Rapport was easily established, as there were many similarities between P5 and her family and the interviewer. P5 answered all questions without hesitation, but her unhappiness about the way girls treated S5 in school was distinctly apparent. P5 spoke with great pride over her daughter's accomplishments, in spite of the challenges of having an autism spectrum disorder.

APPENDIX M
BRIEF SUMMARY AND COMMONALITIES OF
GRADUATED STUDENTS' RESPONSES

Brief Summary and Commonalities of Graduated Student Responses

Guide Question #1: What was your educational experience as a student in this urban school system?

Question	S1	S2	S3	S4	S5	Commonalities
1.1	Not sure. Attention span when things too easy or difficult	Yes; not able to understand details to complete projects	Yes; academic experiences requiring social participation, concentration, less than ideal environmental situations	No; have the same capacity to learn as others	Yes; difficulty with abstract thinking, fine- motor, and gross- motor tasks	Four out of five indicated challenges to learning due to ASD

Question	S1	S2	S3	S4	S5	Commonalities
1.2	Understanding above "book stuff"	Classes with specific assignments	Successful in many classes, preferred creative writing to express himself which helped others like him better	Classes that weren't loud; would lose train of thought	Teachers were structured, gave clear explanations	Two mentioned structure and specificity for successful learning environments

Question	S1	S2	S3	S4	S5	Commonalities
1.3	Where forced to socialize again will	Project-based classes and math application	Strict or restrictive environments	The subject of math was challenging	Geometry because of demanding teacher and drawing constructions; Chemistry because it involved math and science	Math was challenging for three students; social learning activities was mentioned by two students

Question	S1	S2	S3	S4	S5	Commonalities
1.6	Humorous, open-minded	Patience to keep explaining questions	Encouraging, understanding, empathic; would be same for NTs	Sense of humor	Organized, structured, detailed, understanding of needs of ASD, prefers teachers who present visuall	Sense of humor mentioned as an effective teacher characteristic by two students; understanding teachers mentioned by two

Question	S1	S2	S3	S4	S5	Commonalities
1.8	Not successful in school- people judging	High school went well except math (geometry)	Regrets not participating more socially in high school, was focused on academics	It was great	Did not push herself academically	Three students indicated some kind of dissatisfaction about their educational experience

Guide Question #2: What was your social experience as a student in this urban public school system?

Question	S1	S2	S3	S4	S5	Commonalities
2.1	No, diagnosed too late	N	No, but debate or drama would have been helpful	No; didn't want to tell others about his condition	No	None of the students participated in a social skills class

Question	S1	S2	S3	S4	S5	Commonalities
2.3	None	No help for social activities	SPED personnel assisted with questions about social situations; effective, and relationship with teachers endures	No help	No help, decided to do things on her own	Four students had no assistance from school personnel for participation in social activities

Question	S1	S2	S3	S4	S5	Commonalities
2.5	Negative: humiliation, embarrassment, misunderstandings	Neutral; high school was okay, elementary school was not good experience	First two years of high school were rough, got better in 11th grade; detachment, mostly in a world of his own	Positive; focused on education, selective about friendships	Difficulty answering- not positive, maybe neutral; social stimulus makes me anxious; concerned about being judged about responses	Two students indicated social experiences were neutral; two mentioned improvement in high school;

Question	S1	S2	S3	S4	S5	Commonalities
2.6	Negative experience: accused of being serial killer and responded inadequately	Positive experience: had fun making funny pictures with peers in art magnet academy class	Negative (traumatic experiences are vivid); PE traumatic, not athletic, always chosen last, picked on by others	Had a friend in elementary school; can't recall another social experience	Can't recall social experience other than being teased, never had a boyfriend	Two students recall a negative experience; two could not recall a specific experience

Question	S1	S2	S3	S4	S5	Commonalities
2.7	Hellish- never want to do again	Didn't talk much except to peers in art magnet classes	Meaningful relationships developed mostly with teachers	Thinks he could have done better socially, never really had a best friend	No, just don't judge negatively	No subject had anything positive to say about school social experience

Guide Question #3: What do you remember about your involvement and your parents' **involvement in your school** experience?

Question	S1	S2	S3	S4	S5	Commonalities
3.1	Yes- near end; neutral experience; parent participated	Yes; didn't like it; didn't like being the center of attention; parents participated	Yes; meetings were useful, felt comfortable ; parents participated	Went to most meetings; basically felt comfortable; parents went to meetings	Yes, went to meetings; discussed accommodations; parents participated	All students participated in meetings, and all students' parents participated in meetings; three students felt comfortable in the meetings

Question	S1	S2	S3	S4	S5	Commonalities
3.2	Nothing requested	Would rather not have the meeting at all; felt like being sent to the principal's office for doing something wrong	Parents wanted extended time; Student didn't want extended time, would feel inferior to others, but agreed to extended time	Extended time; needed it earlier in school experience, but not later; wasn't included in accommodations	Parents wanted me in drama class; wasn't really interested because she was too shy; took the class anyway	Two students mentioned that parents wanted them to have extended time, but the students didn't want it

Question	S1	S2	S3	S4	S5	Commonalities
3.3	Be more social; wanted to be alone	Be more social; doesn't do proms or group stuff	Have more friends; didn't need a lot of friends, but recognizes the need for broader experience	No; student wanted normal social life	Had the feeling parents wanted her to have more friends; was okay with being alone; contrary to others with Asperger's, she is concerned about what others think of her	Four students indicated that their parents desired more social experiences and friendships

Question	S1	S2	S3	S4	S5	Commonalities
3.4	Yes; over-estimate me: intellect does not make things easier; parent participated; school did little to prepare for post-secondary; college and high school too different	Yes; but it was a group meeting for the Seniors (parents didn't participate); don't recall an individual transition meeting; Poorly; did not learn pre-requisite skills for the Visual Arts college he attended briefly	Yes; continue to meet with Vocational rehabilitation; parents attended; High school taught about a lot of subjects, but still have a lot of uncertainties about what I want to do	Yes; experience was okay; parents participated; school prepared well for post-secondary experience	No transition meeting(504 Plan), decided on college herself	Four out of four of the students participated in the transition meeting; two students felt high school did a poor job of preparing subject for post-secondary school. All students went to college after high school
Question	S1	S2	S3	S4	S5	Commonalities
3.5	No	No	Parents were always there when needed, pushing and providing encouragement--all children need it	Wanted to be independent like most teenagers	There was an identified "go-to" person in the school who helped with problem situations	Two students had nothing further to say about their involvement in school

	S1	S2	S3	S4	S5
Brief Summary	Unsuccessful in school; nothing positive to say; social experiences “nerve wracking and hellish;” received no help for socialization; high intellect does not make it easier to overcome challenges of ASD; knew in theory how to make friends, but couldn’t put it into practice; felt judged by others.	Needed academic work to be specific, step-by-step; made friends with others who had similar interests, but didn’t like social activities involving large groups; felt like he was in trouble and being sent to the principal’s office in IEP meetings; overall, school was a neutral experience.	Academically successful but now recognizes that school is also a social opportunity; didn’t want accommodations that would set him apart from others; participated in social experiences, but felt detached from peers; hung out with “misfits”; easier to have friendships with teachers.	Wanted to be like others, didn’t want others to know he has ASD, didn’t want accommodations that would make him different; felt well-prepared for post-secondary; high school was positive; could have done better socially; no best friend except one with ASD he met in elementary school.	Didn’t push herself academically, thought she could have done better; abstract thought was difficult; cared about what others thought of her; participated in social experiences but wasn’t an active participant; was okay with being alone, less confusing, but didn’t want others to judge her negatively for that.

APPENDIX N
BRIEF SUMMARY AND COMMONALITIES OF PARENTS' RESPONSES

Brief Summary and Commonalities of Parents' Responses

Guide Question #1: What was your experience as a parent of a student with an autism spectrum disorder student a large urban school system in meeting your child's educational needs?

Question	P1	P2	P3	P4	P5	Commonalities
1.1	Yes. Difficulty with socialization made him anxious and would not want to come to school.	Yes. Organization skills, poor social skills and communication skills	Yes. Difficulty learning socially	No. Being autistic he has a well developed memory	Yes. Sensory distractions, social challenges,	Four parents indicated that having an ASD affected child's ability to learn due to social challenges

Question	P1	P2	P3	P4	P5	Commonalities
1.2	Language arts type classes, caring and accepting teachers.	Smaller classes and fun classes, teachers aware of disabilities.	Quieter environments and sitting in front.	History because son watches History Channel, likes math.	Being in mainstream settings rather than self-contained special education classes, specially selected teachers whenever possible.	Three parents indicated that teacher qualities affected child's success in the classroom.

Question	P1	P2	P3	P4	P5	Commonalities
1.3	Math classes, or classes requiring verbal participation; not successful with teachers who use sarcasm or are inconsistent with classroom discipline.	Auditorium type classes.	Group projects, wants to work on his own, doesn't trust others' ability.	Transitions from one school to another: elementary to middle, middle to high school.	Group projects, noisy classrooms.	Two parents indicated that classes with group projects were challenging.
1.5	Use of a laptop would have helped.	Small class sizes.	Preferential seating, extended time, but didn't like to use it.	Being treated like any other child.	Extended time, preferential seating, pass to ASD support prn.	Two parents indicated extended time was helpful

Question	P1	P2	P3	P4	P5	Commonalities
1.6	Structured, accepting, caring.	Sense of humor, organized, fun, smart.	Sense of humor, helps son relax.	Caring, compassionate.	Caring, good communicators.	Three parents indicated a caring teacher was helpful; two parents indicated a sense of humor was a helpful teacher characteristic.

Question	P1	P2	P3	P4	P5	Commonalities
1.7	Positive: elementary teacher encouraged son's reading and writing.	Positive: good math teacher who closely monitored son.	Positive: performed a Shakespeare soliloquy and got very positive feedback from peers.	Son's interest in animals and watching Discovery Channel got son into the Magnet high school which was a good experience.	Parent recalls providing advice to Kindergarten teacher about explaining all the rules about walking in a line to the cafeteria: can't assume daughter knows steps even when obvious.	Four parents related a positive learning experience for their child.

Question	P1	P2	P3	P4	P5	Commonalities
1.8	Limited communication from school problematic.	Private middle school was a disaster - picked on and bullied, public high school very positive.	Except for social life, high school was great.	The transition to high school and learning to be independent was challenging for son.	Hopefully there's more training and information for teachers about high-functioning autism and Asperger's; wish there had been an opportunity for daughter to learn social skills from	No commonalities observed.

					peers in a structured setting.	
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Guide Question #2: What were your child’s social experiences as a student in the large urban school system?

Question	P1	P2	P3	P4	P5	Commonalities
2.1	No. Son diagnosed late (11th grade).	No. Not in public school, had some outside therapy group.	No.	No.	No.	All parents indicated there was no social skills class for their child.

Question	P1	P2	P3	P4	P5	Commonalities
2.2	No. Social situations scared him, no support provided in case of anxiety.	No. Son didn't want to, inability to relate to and communicate with others students.	Yes. Interact, Honor Society, Science Club, Chess Club, and went to Grad Night and Graduation; Happy because son is making effort to socialize.	Yes. Heritage Club, Spanish Club, Grad Night, Senior Prom, Graduation; son was happy; parents were thrilled and concerned, as they still are.	Yes. Prom, Grad Night, Best Buddies, chorus; parent nervous about Grad Night, went to Prom with older male with Asperger's she has known a long time.	Two parents indicated their child did not participate in social experiences; Three parents indicated their child participated and two of those three felt concern about their child's participation.

Question	P1	P2	P3	P4	P5	Commonalities
2.3	None, other than teacher helping at graduation.	None.	No, mother encouraged son to participate.	Magnet teacher encouraged son's participation in some clubs; this was effective.	Not much, ASD teacher went because of lower functioning students; this was helpful.	Three parents indicated that no assistance from school personnel was provided for social experiences.

Question	P1	P2	P3	P4	P5	Commonalities
2.4	<p>Very difficult.</p> <p>Made limited friendships in class but did not maintain outside of class; non-ASD.</p>	<p>Extremely difficult. Don't think friends have ASD.</p>	<p>Difficult in the 9th and 10th grades; friends non-ASD.</p>	<p>Very, very difficult.</p> <p>Has more female friends but parents have not met them, has some FaceBook friends; friends are non-ASD.</p>	<p>Difficult since middle school.</p> <p>Daughter is naïve, ostracized by girls, had difficulty distinguishing between friend and acquaintance; a few older non-ASD friends, ASD neighbor friends & from social groups.</p>	<p>All parents indicated that making friends was difficult to varying degrees.</p>

Question	P1	P2	P3	P4	P5	Commonalities
2.5	Negative.	Non-existent.	Mostly positive.	Unknown, but probably positive.	Negative. Concerned about social naïveté and people taking advantage of her	Two parents indicated that the school social experience was negative; one parent indicated it was non-existent.

Question	P1	P2	P3	P4	P5	Commonalities
2.6	No, son didn't share much except he was picked on.	Negative: love relationship went bad.	Negative: son made emergency phone call to mother after a girl he didn't know kissed him: he wanted to know if it was because she loved him, mother clarified that he was teased.	Don't know of friends from high school, has maintained a phone-contact friendship with boy with ASD from elementary school.	Negative: middle school friend who turned on her with a group of other girls.	Four parents shared a negative school social experience.

Question	P1	P2	P3	P4	P5	Commonalities
2.7	No, didn't have many social experiences.	Wish there had been more experiences.	9th and 10th grade were hard, wish there had been a social skills class.	Son is well liked by teachers.	Negative: girls put applesauce in hair. When it dried, girls teased daughter in front of others stating she had lice, she was sent home; Daughter doesn't trust people; doesn't do anything social which only bothers daughter because she thinks her parents want her to be more social.	Four parents shared challenges with child's school social experiences.

Guide Question #3: **What do you remember about your involvement and your child’s involvement in his/her school experience?**

Question	P1	P2	P3	P4	P5	Commonalities
3.1	Yes. Positive, time to talk with teachers; son rarely participated.	Yes. Good recommendations, but rarely were they all implemented; son participated.	Yes. Good discussions with the teachers; son participated.	Yes. Very good experience to discuss areas where son needed help; son participated in meetings in high school.	Yes. Very, very good experience to get the right accommodations for daughter; daughter participated.	All parents participated in the IEP process, and four children participated in high school.

Question	P1	P2	P3	P4	P5	Commonalities
3.2	Don't recall.	Yes, wanted a note-taking buddy; son didn't want to be singled out in class; never had a note-taking buddy.	Don't recall.	Yes, parents wanted extended time for tests; son didn't want extended time because he didn't want to be different; it was on IEP, but son didn't use it.	No.	Two parents indicated they wanted an academic accommodation, but their child didn't want to be different from others in class.

Question	P1	P2	P3	P4	P5	Commonalities
3.3	Wanted a Senior picture; son refused.	Wanted more social experiences; son didn't want them.	Wanted him to attend Prom; son didn't want to go, so he didn't go.	No.	No, if parents suggested a social activity daughter would usually try.	Three parents wanted more social experiences for child.

Question	P1	P2	P3	P4	P5	Commonalities
3.4	<p>Yes.</p> <p>Disappointed about push toward vocational program rather than college; son participated; not very well prepared, college and high school very different</p>	<p>Yes.</p> <p>Introduced to Vocational Rehabilitation but family didn't follow-up; don't recall son participating; high school did not prepare son for college- it was vastly different and he was lost</p>	<p>Yes.</p> <p>Good communication with Vocational Rehabilitation counselor; son participated; school prepared him well and communicated well with parent</p>	<p>Yes.</p> <p>Very good to discuss options; son participated; good job of preparing for post-secondary but not excellent, high school and college very different</p>	<p>No.</p> <p>Meeting because daughter had a 504 Plan</p>	<p>Four of four parents participated in Transition meeting; two parents indicated school did not prepare child too well for post-secondary experiences; three noted difference between high school, college.</p>

Question	P1	P2	P3	P4	P5	Commonalities
3.5	School did the best it could with the information it had	Communication with school via e-mail and telephone focused on academics, no social life observed	Academic experience was fine, needed a lot of encouragement for social skills	Parental involvement is very, very important	Teacher liaison between parent and staff helpful for problematic situations before it escalates; a "go to" teacher for daughter to see if there was a problem	Two parents mentioned communication with school is important

	P1	P2	P3	P4	P5
Brief Summary	Son had academic challenges due to ASD; needed a caring teacher; social anxieties affected ability to work with others on academic tasks; had few friends; very difficult making friends; no support provided for participation in social experiences; high school and college very different; high school did not prepare well for post-secondary experience.	Overall positive experience in high school; challenged by social learning activities and group projects; needed assistance with organization; social experiences non-existent; great difficulty making friends; parent and child involved in school meetings;	Son's academic challenges were related to activities requiring social participation; academic part of high school was great; participated in many social activities but had difficulty making friends; socially naïve; no social skills class; parent and child	Son has excellent memory due to ASD; difficulty with transitions from one school level to another; son wanted to be treated like any other child; very, very difficult for him to make friends, but well liked by teachers; parents and child participated in all meetings and	Sensory distractions and social challenges affected daughter's learning; extended time, preferential seating and pass to ASD teacher helped; having teachers aware of ASD is important; participated in social activities but was ostracized and victimized; parent
	parent and child participated in meetings.	school did not prepare well for post-secondary since they are so different	participated in IEP and Transition meetings, received good information.	found them useful; parent involvement very important.	Wishes daughter had social skills training with peer mentors; getting accommodations correct was important for daughter's success; teacher liaison between parent and other teachers was a helpful communication tool to handle problems.

APPENDIX O
COMPARISON OF INDIVIDUAL GRADUATE STUDENT RESPONSES
TO PARENT RESPONSES

Student 1 and Parent 1 Responses

Question	S1	P1	S1/P1 Agreement?
1.1	Not sure. Attention span when things too easy or difficult	Yes, difficulty with socialization made him anxious and would not want to come to school	Yes
1.2	Understanding above "book stuff"	Language arts type classes, caring and accepting teachers	Yes
1.3	Where forced to socialize again will	Math classes, or classes requiring verbal participation; not successful with teachers who use sarcasm or are inconsistent with classroom discipline	No
1.4	Mom helped- not sure how	Asked for guidance, not instruction	Yes
1.5	Extended time	Use of a laptop would have helped	No
1.6	Humorous, open-minded, caring	Structured, accepting, caring	Yes
1.7	Memories repressed	Positive: elementary teacher encouraged son's reading and writing	No
1.8	Not successful in school- people judging	Limited communication from school problematic	No
Guide #2			
2.1	No, diagnosed too late	No: son diagnosed late (11th grade)	Yes
2.2	No, except for graduation; it was nerve-racking and sweaty	No; social situations scared him, no support provided in case of anxiety	Yes
2.3	None	None, other than teacher helping at graduation	Yes
2.4	Very difficult; knew how in theory; practice intimidating; few friends	Very difficult, made limited friendships in class but did not	Yes

Question	S1	P1	S1/P1 Agreement?
	are non-ASD	maintain outside of class; non-ASD	
2.5	Negative: humiliation, embarrassment, misunderstandings	Negative	Yes
2.6	Negative experience: accused of being serial killer and responded inadequately	No, son didn't share much except he was picked on	Yes
2.7	Hellish- never want to do again	No, didn't have many social experiences	Yes
Guide #3			
3.1	Yes- near end; neutral experience; parent participated	Yes; positive, time to talk with teachers; son rarely participated	Yes
3.2	Nothing requested	Don't recall	Can't determine
3.3	Be more social; wanted to be alone	Wanted a Senior picture; son refused	No
3.4	Yes; over-estimate me: intellect does not make things easier; parent participated; school did little to prepare for post-secondary; college and high school too different	Yes; disappointed about push toward vocational program rather than college; son participated; not very well prepared, college and high school very different	Yes
3.5	No	School did the best it could with the information it had	Can't determine

Question	S1	P1	S1/P1 Agreement?
Brief Summary	School experience was unsuccessful; no positive comments about school experience; social experiences were nerve-racking and hellish; received no help for socialization; high intellect does not make it easier to overcome social challenges of ASD; knew in theory how to make friends, but couldn't put it into practice; felt he was judged by others.	Son had academic challenges due to ASD; needed caring teacher; social anxieties affected ability to work with others on academic tasks; had few friends; ability to make friends very difficult; no support provided to enable son to participate in social experiences; high school and college very different; high school did not prepare well for post-secondary experience; parent and child participated in meetings.	

Student 2 and Parent 2 Responses

Question	S2	P2	S2/P2 Agreement?
Guide 1			
1.1	Yes; not able to understand details to complete projects	Yes, organization skills, poor social skills and communication skills	Yes
1.2	Classes with specific assignments	Smaller classes and fun classes, teachers aware of disabilities	Yes
1.3	Project-based classes and math application	Auditorium type classes	No
1.4	Explanation of the book	Organization (color coding),	No
1.5	Extended time	Small class sizes	No
1.6	Patience to keep explaining questions	Sense of humor, organized, fun, smart	No
1.7	Would fall asleep in dark auditorium classes. Also frustrated about content of a Commercial Art class	Positive: good math teacher who closely monitored son	No
1.8	High school went well except math (geometry)	Private middle school was a disaster - picked on and bullied, public high school very positive	No
Guide 2			
2.1	No	Not in public school, had some outside therapy group	Yes
2.2	No, except for graduation; don't like big crowds, loud shows; prom "not for me"	No, he didn't want to, inability to relate to and communicate with others students	Yes
2.3	No help for social activities	None	Yes
2.4	Impossible in elementary school; made a few friends in high school; not sure if friends have ASD, they have similar interests	Extremely difficult; don't think friends have ASD	Yes
2.5	Neutral; high school was okay, elementary school was not good experience	Non-existent	Yes
2.6	Positive experience: had fun making funny pictures with peers in art magnet academy class	Negative: love relationship went bad	No

Question	S2	P2	S2/P2 Agreement?
2.7	Didn't talk much except to peers in art magnet classes	Wish there had been more experiences	Yes
Guide 3			
3.1	Yes; didn't like it; didn't like being the center of attention; parents participated	Yes; good recommendations, but rarely were they all implemented; son participated	Yes
3.2	Would rather not have the meeting at all; felt like being sent to the principal's office for doing something wrong	Yes, wanted a note-taking buddy; son didn't want to be singled out in class; never had a note-taking buddy	Can't determine
3.3	Be more social; doesn't do proms or group stuff	Wanted more social experiences; son didn't want them	Yes
3.4	Yes; but it was a group meeting for the Seniors (parents didn't participate); don't recall an individual transition meeting; Poorly; did not learn pre-requisite skills for the Visual Arts college he attended briefly	Yes; introduced to Vocational Rehabilitation but family didn't follow-up; don't recall son participating; high school did not prepare son for college- it was vastly different and he was lost	Yes
3.5	No	Communication with school via e-mail and telephone focused on academics, no social life observed	Can't determine
Brief Summary	Needed academic work to be specific, step-by-step; made friends with others who had similar interests, but didn't like social activities involving large groups of people; felt like he was in trouble and being sent to the principal's office in the IEP meetings; overall, school was a neutral experience.	Overall positive experience with public high school; academic challenges with social learning activities (group projects); needed assistance with organization; social experiences non-existent and had great difficulty making friends; parent and child were involved in school meetings; school did not prepare well for post-secondary experiences since they are so different.	

Student 3 and Parent 3 Responses

Question	S3	P3	S3/P3 Agreement?
Guide 1			
1.1	Yes; academic experiences requiring social participation, concentration, less than ideal environmental situations	Yes, difficulty learning socially	Yes
1.2	Successful in many classes, preferred creative writing to express himself which helped others like him better	Quieter environments and sitting in front	Can't determine
1.3	Strict or restrictive environments	Group projects, wants to work on his own, doesn't trust others' ability	No
1.4	Didn't help because of limited academic background	Support through time management	No
1.5	Extended time, preferential seating	Preferential seating, extended time (although he didn't like to use it)	Yes
1.6	Encouraging, understanding, empathic; would be same for NTs	Sense of humor, helps son relax	No
1.7	Nothing out of the ordinary comes to mind	Positive: performed a Shakespeare soliloquy and got very positive feedback from peers	No
1.8	Regrets not participating more socially in high school, was focused on academics	Except for social life, high school was great	Yes

Question	S3	P3	S3/P3 Agreement?
Guide 2			
2.1	No, but debate or drama would have been helpful	No	Yes
2.2	Yes: National Honor Society, Phi Beta Chi, Mu Alpha Theta, Bridge Club, Interact, liked helping others but felt detached from members, didn't know how to hang around with others	Yes; Interact, Honor Society, Science Club, Chess Club, and went to Grad Night and Graduation; Happy because son is making effort to socialize	Yes
2.3	SPED personnel assisted with questions about social situations; effective, and relationship with teachers endures	No, mother encouraged son to participate	No
2.4	Degree of detachment with others; hung around eccentrics, nerds, misfits; most friends weird	Difficult in the 9th and 10th grades; friends non-ASD	Yes
2.5	First two years of high school were rough, got better in 11th grade; detachment ,mostly in a world of his own	Mostly positive	Can't determine
2.6	Negative (traumatic experiences are vivid); PE traumatic, not athletic, always chosen last, picked on by others	Negative: son made emergency phone call to mother after a girl he didn't know kissed him: he wanted to know if it was because she loved him, mother clarified that he was teased	Yes
2.7	Meaningful relationships developed mostly with teachers	9th and 10th grade were hard, wish there had been a social skills class	Can't determine

Question	S3	P3	S3/P3 Agreement
Guide 3			
3.1	Yes; meetings were useful, felt comfortable ; parents participated	Yes; good discussions with the teachers; son participated	Yes
3.2	Parents wanted extended time; didn't want extended time, would feel inferior to other students; agreed I should have extended time	Don't recall	Can't determine
3.3	Have more friends; didn't need a lot of friends, but recognizes the need for broader experience	Wanted him to attend Prom; son didn't want to go, so he didn't go	No
3.4	Yes; continue to meet with Vocational rehabilitation; parents attended; High school taught about a lot of subjects, but still have a lot of uncertainties about what I want to do	Yes; good communication with Vocational Rehabilitation counselor; son participated; school prepared him well and communicated well with parent	Yes
3.5	Parents were always there when needed, pushing and providing encouragement-- what all children need	Academic experience was fine, needed a lot of encouragement for social skills	Yes

Question	S3	P3	S3/P3 Agreement?
Brief Summary	Academically successful but recognizes now that school is also a social opportunity; didn't want accommodations that would make him different from others; participated in social experiences but felt detached from others (peers); more comfortable relationships with teachers.	Son's academic challenges were related to activities requiring social participation; academic part of high school was great; participated in many social activities but had difficulty making friends; socially naive; no social skills class; parent and child participated in IEP and Transition meetings and received good information.	

Student 4 and Parent 4 Responses

Question	S4	P4	S4 /P4 Agreement?
Guide 1			
1.1	No; have the same capacity to learn as others	No, being autistic he has a well developed memory	Yes
1.2	Classes that weren't loud; would lose train of thought	History because son watches History Channel, likes math	No
1.3	The subject of math was challenging	Transitions from one school to another: elementary to middle, middle to high school	No
1.4	Got a tutor for math and science, parents helped when they had time	Structure	Yes
1.5	Preferential seating	Being treated like any other child	No
1.6	Sense of humor	Caring, compassionate	No
1.7	Positive: made a Senior memory book in English class	Son's interest in animals and watching Discovery Channel got son into the Magnet high school which was a good experience	Can't determine
1.8	It was great	The transition to high school and learning to be independent was challenging for son	Can't determine
Guide 2			
2.1	No; didn't want to tell others about his condition	No	Yes
2.3	No help	Magnet teacher encouraged son's participation in some clubs; this was effective	No

Question	S4	P4	S4 /P4 Agreement?
2.4	No friends first two years of high school; decided to put more effort into getting friends during Junior and Senior year; friends did not have ASD	Very, very difficult, has more female friends but parents have not met them, has some facebook friends; friends are non-ASD	Yes
2.5	Positive; focused on education, selective about friendships	Unknown, but probably positive	Yes
2.6	Had a friend in elementary school; can't recall another social experience	Don't know of friends from high school, has maintained a phone-contact friendship with boy with ASD from elementary school	Yes
2.7	Thinks he could have done better socially, never really had a best friend	Son is well liked by teachers	No
Guide 3			
3.1	Went to most meetings; basically felt comfortable; parents went to meetings	Yes; very good experience to discuss areas where son needed help; son participated in meetings in high school	Yes
3.2	Extended time; needed it earlier in school experience, but not later; wasn't included in accommodations	Yes, parents wanted extended time for tests; son didn't want extended time because he didn't want to be different; it was on IEP, but son didn't use it	Yes
3.3	No; student wanted normal social life	No	Yes

Question	S4	P4	S4 /P4 Agreement?
3.4	Yes; experience was okay; parents participated; school prepared well for post-secondary experience	Yes; very good to discuss options; son participated; good job of preparing for post-secondary but not excellent, high school and college very different	Yes
3.5	Wanted to be independent like most teenagers	Parental involvement is very, very important	No
Brief Summary	Wanted to be like others- didn't want others to know about ASD and didn't want accommodations that would make him different; felt well-prepared for post-secondary and school was a positive experience; could have done better socially, doesn't have a best friend other than friend with ASD made in elementary school.	Son has excellent memory due to ASD; had difficulty with transitions from one level school to another; son wanted to be treated like any other child; very, very difficult time making friends, but was well liked by teachers; parents and child participated in IEP and Transition meetings and found them useful; parental involvement very important.	

Student 5 and Parent 5 Responses

Question	S5	P5	S5 /P5 Agreement?
Guide 1			
1.1	Yes; difficulty with abstract thinking, fine-motor, and gross-motor tasks	Yes, sensory distractions, social challenges,	Yes
1.2	Teachers were structured, gave clear explanations	Being in mainstream settings rather than self-contained special education classes, specially selected teachers whenever possible	Can't determine
1.3	Geometry because of demanding teacher and drawing constructions; Chemistry because it involved math and science	Group projects, noisy classrooms	No
1.4	Had a tutor for science, mother helped with math	Tutors from 4th grade on, usually for science and English	Yes
1.5	Extended time	Extended time, preferential seating, and pass to see ASD teacher when needed	Yes
1.6	Organized, structured, detailed, understanding of needs of ASD, prefers teachers who present visually	Caring, good communicators	Yes

Question	S5	P5	S5 /P5 Agreement?
1.7	Didn't excel in a particular subject, no recollection of particular experience	Parent recalls providing advice to Kindergarten teacher about explaining all the rules about walking in a line to the cafeteria: can't assume daughter knows all the steps involved even though it is obvious to others	No
1.8	Did not push herself academically	Hopefully there's more training and information for teachers about high-functioning autism and Asperger's; wishes there had been an opportunity for daughter to learn social skills from peers in a structured setting	Can't determine
Guide 2			
2.1	No	No	Yes
2.2	Went to graduation and Prom, was in the background at Prom, participated in Best Buddies and chorus as a passive member	Prom, Grad Night, Best Buddies, chorus; parent nervous about Grad Night, went to Prom with older male with Asperger's she has known a long time,	Yes
2.3	No help, decided to do things on her own	Not much, ASD teacher went because of lower functioning students; helpful	Yes

Question	S5	P5	S5 /P5 Agreement?
2.4	Difficult, was a loner; acquaintances without ASD but most friendships haven't worked out	Difficult from middle school on, daughter is naïve and was ostracized by girls, had difficulty distinguishing between a friend and an acquaintance; few non-ASD friends who are older, has ASD friends from neighborhood and social groups	Yes
2.5	Difficulty answering- not positive, maybe neutral; social stimulus makes me anxious; concerned about being judged about responses	Negative, concerned about social naivete and people taking advantage of her	
2.6	Can't recall social experience other than being teased, never had a boyfriend	Negative: middle school friend who turned on her with a group of other girls	No
2.7	No, just don't judge negatively	Negative: girls pretending to touch daughter's hair on flattery, only to put applesauce in her hair. When it dried, the girls teased her daughter in front of others stating that she had lice, and she was sent home; She doesn't trust people; Daughter doesn't do anything social which only bothers daughter because she thinks her parents want her to be more social	Can't determine

Question	S5	P5	S5/P5 Agreement?
Guide 3			
3.1	Yes, went to meetings; discussed accommodations; parents participated	Yes; very, very good experience to get the right accommodations for daughter; daughter participated	Yes
3.2	Parents wanted me in drama class; wasn't really interested because she was too shy; took the class anyway	No	No
3.3	Had the feeling parents wanted her to have more friends; was okay with being alone; contrary to others with Aspergers, she is concerned about what others think of her	No, if parents suggested a social activity daughter would usually try	Yes
3.4	No transition meeting(504 Plan), decided on college herself	No meeting because daughter had a 504 Plan	Yes
3.5	There was an identified "go-to" person in the school who helped with problem situations	Having a teacher be liaison between parent and rest of staff is helpful to handle problematic situations before it escalates; this teacher was also the "go to" person for daughter to see if there was a problem	Yes

<p>Brief Summary</p>	<p>Didn't push herself academically, thought she could have done better; abstract thought was difficult; cared about how others felt about her; participated in social experiences but wasn't an active participant; was okay with being alone, but didn't want others to judge her negatively for that.</p>	<p>Sensory distractions and social challenges affected daughter's learning; extended time, preferential seating and pass to ASD teacher helped; having teachers aware of ASD is important; participated in social activities but was ostracized and victimized; parent wishes daughter had social skills training with peer mentors; getting accommodations correct important for daughter's success; teacher liaison between parent and teachers helpful communication tool to handle problems.</p>	
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APPENDIX P
COMPARISON OF GRADUATED STUDENT COMMONALITIES TO
PARENT COMMONALITIES

Question	Graduated Student Commonalities	Parent Commonalities	Agreement?
Guide 1			
1.1	Four out of five indicated challenges to learning due to ASD	Four parents indicated that having an ASD affected child's ability to learn due to social challenges	Yes
1.2	Two mentioned structure and specificity for successful learning environments	Three parents indicated that teacher qualities affected child's success in the classroom	Yes
1.3	Math was challenging for two subjects; social learning activities was mentioned by two students	Two parents indicated that classes with group projects were challenging	Yes
1.4	Two subjects had tutors two subjects got assistance from parent(s)	Four parents provided home learning assistance through structure and guidance	Yes
1.5	Extended time was a helpful accommodation for four subjects; preferential seating mentioned by two subjects	Two parents indicated extended time was a helpful learning accommodation	Yes
1.6	Sense of humor mentioned as an effective teacher characteristic by two subjects; understanding teachers mentioned by two	Three parents indicated a caring teacher was helpful; two parents indicated a sense of humor was a helpful teacher characteristic	Yes
1.7	Three subjects had no specific recollection of learning experience	Four parents related a positive learning experience for	No

Question	Graduated Student Commonalities	Parent Commonalities	Agreement?
		their child	
1.8	Three subjects indicated some kind of dissatisfaction about their educational experience		Can't determine
Guide 2			
2.1	None of the subjects participated in a social skills class	All parents indicated there was no social skills class for their child	Yes
2.2	Two subjects did not participate in school clubs or activities; two subjects participated but did not feel connected to others	Two parents indicated their child did not participate in social experiences; Three parents indicated their child participated and two of those three felt concern about their child's participation	Yes
2.3	Four subjects had no assistance from school personnel for participation in social activities	Three parents indicated that no assistance from school personnel was provided for social experiences	Yes
2.4	All subjects had challenges making friends; three subjects knew the friends they had did not have ASD	All parents indicated that making friends was difficult to varying degrees	Yes

Question	Graduated Student Commonalities	Parent Commonalities	Agreement?
2.5	Two subjects indicated social experiences were neutral;	Two parents indicated that the school social experience was negative; one parent indicated it was non-existent	No
2.6	Two subjects recall a negative experience; two could not recall a specific experience	Four parents shared a negative school social experience	Yes
2.7	No subject had anything positive to say about school social experience	Four parents shared challenges with child's school social experiences	Yes
Guide 3			
3.1	All subjects participated in meetings, and all subjects' parents participated in meetings; three students felt comfortable in the meetings	All parents participated in the IEP process, and four children participated in high school	Yes
3.2	Two subjects mentioned that parents wanted them to have extended time, but subjects didn't want it\	Two parents indicated they wanted an academic accommodation, but their child didn't want to be different from others in class;	Yes
3.3	All subjects indicated that their parents desired more social experiences / friendships	Three parents wanted more social experiences for child	Yes

Question	Graduated Student Commonalities	Parent Commonalities	Agreement?
3.4	Four out of four of the subjects participated in the transition meeting; two subjects felt high school did a poor job of preparing subject for post-secondary school. All subjects went to college after high school	Four out of four parents participated in the Transition meeting; two parents indicated that school did not prepare child too well for post-secondary activities; three parents mentioned that high school and college are very different	Yes
3.5	Two subjects had nothing further to say about their involvement in school	Two parents mentioned communication with school is important	Can't determine

APPENDIX Q
SPSS OUTPUT: COHEN'S KAPPA STATISTICAL INFORMATION

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Scorer1a * Scorer2a	120	100.0%	0	.0%	120	100.0%

Scorer1a * Scorer2a Crosstabulation

Count

		Scorer2a			Total
		0	1	2	
Scorer1a	0	15	0	0	15
	1	5	25	1	31
	2	0	0	74	74
Total		20	25	75	120

Symmetric Measures

		Value	Asymp. Std. Error(a)	Approx. T(b)	Approx. Sig.
Measure of Agreement	Kappa	.907	.036	13.335	.000
N of Valid Cases		120			

a Not assuming the null hypothesis.

b Using the asymptotic standard error assuming the null hypothesis.

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