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Social Experiences of Adolescents with High Functioning Autism (HFA) and/or Asperger Syndrome (AS) - Their Perceptions and Their Views of Their Caregivers: An Exploratory Study

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LOYOLA UNIVERSITY CHICAGO

SOCIAL EXPERIENCES OF ADOLESCENTS WITH HIGH FUNCTIONING
AUTISM (HFA) AND/OR ASPERGER'S SYNDROME (AS) – THEIR PERCEPTIONS
AND THE VIEWS OF THEIR CAREGIVERS: AN EXPLORATORY STUDY

A DISSERTATION SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL
IN CANDIDACY FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

PROGRAM IN SOCIAL WORK

BY

PATRICIA A. KUNZ, LCSW

CHICAGO, ILLINOIS

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ABSTRACT

This study used the Grounded Theory methodology to investigate, through an exploratory manner, the social experiences of adolescents with High Functioning Autism (HFA) and/or Asperger's Syndrome (AS) as shared by the adolescents themselves, and the views of their parent/caregivers regarding this experience. In addition, the adolescents and parents shared their thoughts on having and managing a diagnosis of HFA/AS and the current adaptive behaviors of the adolescents.

Seven adolescents and their respective parent caregivers participated in video-taped paired interviews. The themes emergent from the interviews regarding the diagnosis of HFA/AS for the parents were: *rejection, feeling blamed, emotional toll and management of the disorder*. For the adolescents emergent themes were: *indifference, distancing from diagnosis* through use of third person, plural and singular, and *perceived positives and negative of having HFA/AS*. The emergent themes and patterns regarding the experiences of the parent caring for an adolescent with HFA/AS along with the adolescents' shared thoughts on the diagnosis illuminated the overt worry of the caregivers juxtaposed to a seemingly indifferent response by their adolescents.

Information shared regarding the adolescents adaptive behaviors revealed that the adolescents participating in this study, although all of average to above average intelligence, lacked independence with an overall reliance on mother.

From different vantage points the adolescents and their caregivers shared corresponding themes of social experiences: *restricted social circle, object-oriented connections rather than emotional ties, isolation, both self-sort and imposed and outsider.*

The results of this study were discussed in terms of the objectives of this study, and its limitations.

CHAPTER I

INTRODUCTION AND LITERATURE REVIEW

Introduction and Rationale for the Study

The purpose of this study is to explore the social experiences and adaptive behaviors of adolescents with high functioning autism and/or Asperger's Syndrome at home, school and in other programs, and the community. Information will be gathered through: a questionnaire completed by the adolescent's parent/caregiver and two video-taped interviews – one with the adolescent and one with the parent/caregiver.

Following an Exploratory research format incorporating the Grounded Research Method, emergent themes from the interview data and information from the questionnaire will be used to inform on the following: (1) Parent/Caregivers' views of the social experiences of their adolescents with HFA/AS. (2) Adolescents with HFA/AS personal view of their social experiences. (3) How these two views compare. (4) Based on interview questions adapted from the Vineland-II Adaptive Behavior Scales (2005) from sections on Communication, Daily Living, and Social Skills and Relationships the adolescent's level of participation in relational adaptive behaviors within the home and community.

Current literature indicates the paucity of studies with regards to the social experiences and adaptive behaviors of adolescents with HFA/AS and the dearth of interventions for children with autism as they mature. Additionally, the voice of high

functioning adolescents with autism is seldom heard even though studies indicate individuals with HFA/AS are quite capable in terms of language and cognitive skills.

In conducting an Exploratory study it is expected that the essence of the adolescent's social and adaptive experiences, and the view of the parent/caregiver will increase the knowledge base and processes of adolescent development and social interactions within the context of living with a diagnosis of high functioning autism (HFA) and/or Asperger's Syndrome (AS). HFA and AS will be used by the author throughout this proposal as a matter of convenience and consistency; however, other representations for the diagnosis of autism and abbreviations will be used as reported by other authors' works cited.

Literature Review

Autism - Its Beginnings to Present Time

Since the first introduction of autism to the psychiatric community by Leo Kanner in 1943 and the subsequent discovery in the 1980s of pediatrician Hans Asperger's work, also during the early 1940s, with children similar to those Kanner encountered (Frith, 1990; Wing, 1999), the official coding for the diagnosis of autism has gone through several nomenclatures to emerge as one of the most commonly occurring behavioral disorder in pediatrics (Gabriels & Hill, 2002; Steinhausen & Verhulst, 1999). Autism has come to be considered a life-long developmental disability and as such requires on-going research to address support for appropriate interventions across the life-span for individuals who suffer from this disorder.

Kanner's (1943) original paper "Early Infantile Autism" gave detailed descriptions of his observations of children's behavior which included: profound lack of affective (emotional) contact with other people; intense insistence on sameness in their self-chosen, often bizarre and elaborate repetitive routines; muteness or marked abnormality of speech; fascinations with and dexterity in manipulating objects; high levels of visio-spatial skills or rote memory in contrast to learning difficulties in other areas; attractive, alert, and intelligent appearance (Kanner, 1943; Wing, 1999, p.19).

Around the same time as Kanner (1943) was discovering autism in the United States, Hans Asperger (1944) was working in the University Pediatric Clinic in Vienna, Austria without any connection, Asperger encountered and began to work with a group of children to whom he gave almost the same attributes as Kanner had given to his patients. Asperger published his first paper – in German – in 1944, and considered the most important features of his syndrome and his patients' characteristics as: naïve, inappropriate, social approaches to others; intense circumscribed interest in particular subjects such as railway timetables; good grammar and vocabulary but monotonous speech used for monologues, not two-way conversation; poor motor co-ordination; level of intellect in the borderline, average or superior range but often with specific learning difficulties in one or two subjects; a marked lack of common sense (Asperger, 1944; Frith, 1991; Wing, 1999, p. 20). These men are considered the legitimate "fathers" of autism even though tales, legends, and clinical observations abound in the literature concerning children/adults who were characterized as insane, remote and/or strange (Brauner & Brauner, 1986; Frith, 1989, 1991; Lane, 1977; Maudsley, 1867; Wing &

Potter, 2002), and who, in retrospect, are considered children/adults with what is now known as autism.

Diagnosis and Etiology of Autism

There are three observable characteristics or impairments of autism that have remained consistent since Kanner and Asperger first made their observations. These are sometimes referred to as the triad of impairments or core deficits of autism: Impairment of Social Interaction; Impairment of Communication; and Repetitive Stereotyped Activities (DSM-IV-TR 2000; Frith 1989, 1993; Gutstein 2000; Steinhausen & Verhulst, 1999; Wing 1999). However, over the course of time the etiology and mode of treatment have taken anything but a consistent course.

Over the years since Leo Kanner and Hans Asperger first made their observations, and the eventual manifestation of these features into the criteria for Autistic Disorder, and Asperger's Disorder, much controversy has been stirred up – not only around the etiology of autism itself, but also over the existence of *two* distinct diagnoses, namely, a “high functioning” Autistic Disorder versus Asperger's Disorder/Syndrome (Ghaziuddin, 2005; Klin, Volkmar & Sparrow, 2000; Ozonoff, 1998; Romanowski-Bashe & Kirby, 2005; Siegel, 2003; Wing, 1999, 2000).

Prior to the early sixties, when psychoanalytic theory was prevalent, autism was considered an emotional disorder with the onus of its origin stemming from cold and frigid parenting. Fresh ideas emerging in the late sixties through the eighties, and on into the twenty-first century have moved away from an emotional etiology of autism, rooted in parental interactions with their child, towards a developmental one. Sigman and

Capps (1997, p. 171), and others (Steinhausen & Verhulst, 1999) note, however, autism is not a unitary disease with a single etiology but a heterogeneous behavioral syndrome found in association with many etiologies.

Genetic factors, neurological concepts, and deficits in social cognition have led, and continue to lead, to different approaches and conceptualizations that help to inform one to the other, the complex and puzzling disorder that is autism. Autistic disorders have been found in association with physical conditions that are genetic in origin such as tuberose sclerosis that causes patches of abnormal tissue in the brain, skin and other organs, and phenylketonuria, a biochemical abnormality that is now treatable through diet (Wing, 1996, p. 69). Onset of epilepsy during the first year of life or during childhood and adolescence is another medical condition where the highest risk for this is among persons with mental retardation and autism, and an increased risk for those with normal intelligence (Gillberg & Steffenburg, 1987, Goode et al., 1994; Olsson et al., 1988; Steinhausen & Verhulst, 1999). It is also now believed that 75% of children with autism suffer from mental retardation and the remaining 25%, who are not cognitively delayed and who generally develop fluent speech, present on the Pervasive Developmental Disorder spectrum under Autistic Disorder without mental retardation or Asperger's Disorder (DSM-IV-TR, 2000; Rhode & Klauber, 2004; Rutter, 1979; Sigman & Capps, 1997).

In DSM-IV-TR the term high functioning autism (HFA) is not used but is usually known as Autistic Disorder without mental retardation, and Asperger's Syndrome is generally referred to as Asperger's Disorder. As under the 'Differential Diagnosis' in the

DSM-IV-TR (p. 71), “Asperger’s Disorder can be distinguished from Autistic Disorder by the lack of delay or deviance in early language development.” and under ‘Diagnostic Features’ (p. 81) as “...no clinically significant delays in cognitive development or in age-appropriate self-help skills...” In other words the only discerning factor between what is known as Autistic Disorder without mental retardation and Asperger’s Disorder according the DSM-IV-R is the failure or delay of language acquisition around the expected developmental milestones and delays in age appropriate self-help skills.

The conceptualization of definitions for psychiatric conditions, as purported by American Psychiatric Association in the DSM, stem from a “clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and that is associated with present distress ... or disability...” (DSM-IV-TR, 2000, p. xxxi).

Therefore, a psychiatric diagnosis simply means that a patient has a set of observable behavioral characteristics and the underlying etiology is not necessarily known. This is certainly true of Autism.

Although the American Psychiatric Association recognized Asperger’s Disorder in 1994 as a clinical diagnosis separate from that of autism under the overarching class of Pervasive Developmental Disorders, the debate as to whether children with Autistic Disorder without mental retardation (HFA) and Asperger’s Disorder (AS) are in fact one of the same or two distinct diagnoses or just a hierarchical classification (Ghaziuddin & Mountain-Kimchi, 2004; Gilchrist, Green, Cox, Burton, Rutter, & La Couteur, 2001; Sigman & Capps, 1997) is still on-going. However, as children with Autistic Disorder without mental retardation and children with Asperger’s Disorder mature there are few

statistically significant differences between the two groups' language skills, although generally those with Autistic Disorder keep verbal interaction to a less voluble level than their Asperger's Disorder counterparts (Rhea, Lawrence, Shriberg, McSweeny, Cicchetti, Klin, & Volkmar, 2005). What seems to have remained constant is that a diagnosis of Autistic Spectrum Disorder (ASD) including Autistic Disorder without mental retardation (HFA) and Asperger's Disorder (AS) shows strong stability over time and most children diagnosed with an ASD continue to meet the criteria for the core deficits of autism as adolescents and young adults (McGovern & Sigman, 2005; Mesibov et al., 1989). This means there are more similarities between individuals with HFA and AS with regards to significant difficulties in social understanding and social relationships than differences (Kasari & Rotheram-Fuller, 2005; Laurent & Rubin, 2004). It has been suggested that the combination of normal intelligence and ability to communicate and understand communication – albeit differently than the expected norm – tends to lead persons with HFA/AS to view themselves negatively within the context of their changing and transitioning development and social environments (Capps, Kasari, Yirmiya, & Sigman, 1993; Ghaziuddin, Ghaziuddin & Greden, 2005; Sigman, Dissanayake, Arbelle, & Rushkin, 1997). It is these common difficulties in the developing adolescent with HFA or AS that are of most interest to this researcher who will therefore include subjects falling under both diagnoses within the context of this research.

The Processes of Normal Child Development in Juxtaposition to Autism

Autism is recognized by and through its divergence from normal development. Idiosyncratic behaviors of infants and toddlers who are either in the process of being diagnosed with autism or who already have such a diagnosis are tied to retrospective and growing recognition by parents of their child's limited social responsiveness as well as observations by clinicians and school professionals (Sigman & Capps, 1997). As a child ages, times of psychosocial transitions such as starting secondary school, the shifting from family to more peer based interactions as well as physiological growth (Klin et al., 2000; Shaked & Yirmiya, 2003) all merge to create for some what maybe the perfect storm. The transition from childhood to adolescence is a critical one and one that maybe fraught with difficulties especially when considering children who are deemed at risk either through environmental or mental conditions.

Konopka (1973) devoted much of her professional career to the study of at risk youth and the promotion of programs aimed to facilitate the healthy development of adolescents. Although Konopka's work did not specifically mention adolescents with HFA/AS she believed that all young persons required the provision of certain opportunities to not only cultivate the capacity to enjoy life but also to interact with peers and acquire a sense of belonging. The core deficits of autism: impairments of social interaction; impairment in communication and imagination, and repetitive pattern(s) of behavior, strike at the heart of such interactions *and* the most fundamental but increasingly complex processes of the development of psychosocial interrelationships or in other words – the art of belonging. Therefore, every opportunity should be taken to

assess, promote and implement research based interventions that advance the acquisition of the intrinsic qualities of social interaction throughout the developmental process for those who fall on the autistic spectrum.

For persons diagnosed with Autism Spectrum Disorders (ASD) such as HFA the recognition of delays in development generally emerge, as has been mentioned, during the initial stages of speech acquisition as an infant, and for those with AS, the lack of expected social interactions with others when emerging from toddler-hood (DSM-IV-TR, 2000; Frith, 1990; Sigman & Capps, 1997; Wing, 1999). Psychologically healthy development and emergence from adolescence to young adulthood can vary in continuity relating to and dependent upon opportunities or “stifling experiences” (Schulenberg, Bryant & O’Malley, 2004). Within the traditional theory of normal child development certain skills and changes occur along a unidirectional progression of development marked with achievement milestones allowing for a range of expected physical, biological, psychological and cultural accomplishments within certain time and age periods (Havighurst, 1952). Due to the lack of constancy and invariance within the realm of traditional aspects of human development a person with HFA/AS manifests (Sigman & Capps, 1997) a bridge must be sought between the more traditional aspects of development and current theories of development that explore dynamic living systems as well as development of the teenage brain (Jacobs & Klaczynski, 2002; NIMH, 2001; Schore, 2003; Thomas, 2001). Recent advancements in technology – namely brain imaging – have enabled scientists to explore the neural architecture and specific changes in grey and myelinated white matter during puberty and adolescence (Blakemore &

Choudhury, 2006). These changes occur during a complex time where body, mind, social, affective, and perceptual functions “tornado” together as much for an adolescent with HFA/AS as a normal developing adolescent. A time has come, therefore, for exploration into the social experiences and adaptive manifestations of adolescents with HFA/AS and the interventions and supports.

Adolescents with HFA/AS – inferring overall IQs of 75 or above, continue to experience and struggle with verbal and nonverbal concepts and the ability to express their emotions as other “normal” developing persons. As the focus of normally developing adolescents turns to concepts and possibilities of life and the evaluations and opinions of peers, adolescents with HFA/AS remain within a vortex of social and verbal limitations despite what is seen by several experts on autism as heroic efforts by these adolescents to use intellectual skills to mask and compensate for their interpersonal skills deficits (Capps & Sigman, 1996; Happe, 1994; Hermelin & O’Connor, 1970; Sigman, 1996; Sigman, Yirmiya & Capps, 1995).

Sigman and Capps (1997) note that:

One of the greatest difficulties we face in attempting to understand autism is that the meaning of autistic persons’ idiosyncratic behaviors cannot be inferred directly from knowledge of normally developing persons. Rather than interpreting such behaviors as we would those of a nonautistic person, we must locate them within the puzzling composite of strengths and weaknesses that is autism (p. 27).

The very heterogeneity of autism makes for not only an inquiry into the nature and appropriateness of interventions but also for personal accounts from those with autism -- in this case, adolescents. After working closely with children and adolescents with HFA/AS over a period of ten years within both educational and clinical settings I

have observed adolescents with HFA/AS are rarely given the opportunity to express their point of view regarding social experiences. This research had the intention of exploring the aspects of social experiences as shared by adolescents with the intention of comparing their stories with those of their parent/caregivers.

Autism as a Disability Under IDEA and Special Education

In 1990 *Autism* was added to the categories of disabilities under Subpart A of The Individuals with Disabilities Education (IDEA) regulation. From 1990 to 2004 when Congress reauthorized IDEA with the Improvement Act of 2004 (IDEIA, 2004), autism's growth rate has skyrocketed. Although the majority of the increase is attributed to young children (Hollenbeck, 2004), children diagnosed in the later part of the 1990s are and/or will age into adolescence within the next seven year span.

Although it was possible for students with autism to receive services before this addition under other disability categories, for example: Other Health Impaired (OHI), the specificity of Autism as a category in its own right opened the door for the practice of – or demand for – interventions pertinent to Autistic Spectrum Disorders (ASD). In other words, a collaborative effort could now be made between professional school staff and parents of a child with autism to create an Individualized Educational Plan (IEP) designed to address the specific needs of a student with an ASD, and the subsequent provision of an optimal school learning environment (Bateman & Linden, 1998; Hart, 1993). Lord et al. (2001), through a study under the auspices of the National Academy of Sciences, consider that with regards to the influence of educational and treatment interventions for children with autism no single education or treatment area should be

considered as existing in a vacuum. The inter-relationships between home, school and community and the use of multi-methodologies should be taken into consideration when it comes to developing stable educational programs for individuals with autism (Bunsen, 2002).

Time spent at school provides the opportunity for children and adolescents to interact with their peers and begin to build social and relationship skills as well as academic prowess to prepare them for their future in the adult world. Data gathered through a Special Education Elementary Longitudinal Study (SEELS) (Wagner et al., 2002), explored what was termed the “other” 80% of waking hours experienced by 11,512 special education students, aged between 6 and 12, with disabilities, outside of school. The study focused on three main categories: (1) family support for education at home; (2) interactions with friends; (3) participation in extracurricular activities. Results indicated that 90% of students had occasional or frequent visits with friends each week (occasionally, 3 to 4 times; frequently, more than 4 times). However, it was noted that students with autism had much less frequent contact with friends when compared with other individuals with other disabilities. Within the context of this study 32.3% of students with autism had never visited with a friend compared to 10.3% of students with an Emotional Disturbance. Eighty-one percent of students with autism had rarely or never received telephone calls from friends, compared to 48.7% of students with a hearing impairment. Only 68.1% of students with autism had been invited to other children’s social activities compared to 73.8% of children with Multiple Disabilities. When compared to students with Speech/Language impairment only 9.1% of students

with autism contacted friends through the internet compared to 21.9%. The percentage of students with autism who participated in *none* of the above mentioned social interactions was 11.8%, compared to other students with the following disabilities: .1 with Learning Disability; .5, Speech/Language; 3.1, Mental Retardation; 2.1 Emotional Disturbance; .8 Hearing Impaired; 2.3 Visual Impaired; 2.3 Orthopedic Impairment; 2.0 Other Health Impaired; 2.9 Traumatic Brain Injury; 6.0 Multiple Disabilities. In other words it is evident, from this study, that children with autism for whatever reason(s) have extremely limited social relational interactions with peers.

Even though time spent in school only represents a portion of a student's day it is still the place where regular contact can be made between professionals, the child with HFA/AS and his or her family, and a place where consistent interventions can be practiced. Very importantly, bridges can be built to extracurricular activities with the possibilities of social relationships being developed, and in the case of middle and high school students an arena to construct well thought out transitional plans for life in high school and beyond.

Children diagnosed with Autistic Disorder who are higher functioning tend to have fewer academic problems than children with Asperger's Disorder (Mandell, Walrath, Manteuffel, Sgro, & Pinot-Martin, 2005). Klin et al. (1995) found that the Verbal and Performance IQs of non-retarded individuals with autism are fairly comparable whereas for individuals with AS Verbal scores may outweigh Performance scores (Ehlers et al., 1997; Ozonoff et al., 1991; Siegel et al., 1996).

As children with HFA/AS enter adolescence the propensity to do well academically in specific subjects combined with normal physical appearance often lead to the misreading of such individuals proclivity to fail miserably in peer social interactions and relationships – particularly as their interactions with adults is comparable to chronological and mental age peers (Hauck, Fein, Waterhouse, & Feinstein, 1995; Travis & Sigman, 1998; Volkmar & Kiln, 1995). One cannot help but question whether adolescents with HFA/AS are receiving appropriate interventions and/or treatments to address their social developmental needs, regardless of their academic abilities.

Prevalence and Comparisons to Other Disabilities

The cumulative growth rate for special education services provided to children with autism has gone from 22% in 1993 to 805% in 2003. From 1993 to 2003 the number of cases for individuals 6-22 years of age cumulative growth for all other disabilities under IDEA went from 3% to 31%. From 1993 to 2003 the number of cases for the same age group - cumulative growth for autism went from 22% to 805% (www.ideadata.org and www.ede.gov/nchs). Rates of growth reported by researchers who specialize in autism outside of special education also show prevalence rates changing over time from around 5 per 10,000 up to 62.6 per 10,000 (Accardo & Bostwick, 1999; Chakrabarti & Fombonne, 2001; Lutfiyya et al., 2001; Yeargin-Allsopp et al., 2003; Wing, 1999).

It is not possible to determine clearly the percentage of adolescents with HFA/AS within statistical studies reviewed; however, the study conducted by Lutfiyya et al. (2001) calculated population-based estimates for the nuclear disorder of autism (ND) as

well as the full spectrum of disorders (ASD). For the ages 11-17 years ND prevalence rate of 9.49 (± 2.74) and for ASD 16.30 (± 3.59) per 10,000. Additionally, adolescent/young adults between the ages of 18-21 showed prevalence estimates for ASD of 12.22 (± 4.10) and a ND prevalence estimate of 6.47 ($\pm 2.9[8]$) per 10,000.

Along with the diagnostic controversy over whether HFA and AS are one or the same diagnosis, questions are being raised with regard to the prevalence of autism and its reported epidemic raise. Reliability of the United States Department of Education (USDE) data on the prevalence of autism is reviewed by Laidler (2006), and anomalies in the data – such as unexpected reduction of cases around 12 years of age and significant numbers of new cases among 17 year old adolescents and “nearly linear rise in autism prevalence within a birth-year cohort as it ages” are seen as problems in the data especially as such data is used to influence public policy with regards to services and interventions for persons with autism. However, as these controversies continue there are undoubtedly infants, children, adolescents and adults suffering from the condition that is autism within our communities and schools.

Many school districts are “still debating whether social development is even considered an educational objective” (Lord, 2001). As mentioned above, the longitudinal special education study (SEELS, 2002) studies leisure time spent outside of school and indicates that students with the diagnosis of autism have none to least amount of social interactions compared with all other students with disabilities as categorized under the Individuals with Disabilities Education Act (IDEA). A sense of urgency within the public school system is now being generated due to the indicated increase in prevalence

rates of ASD (Noland & Gabriels, 2004). Estimates for children with some type of ASD reach as high as 6.7 in 1,000 and for children meeting the full criteria for the diagnosis of Autistic Disorder (as defined in the DSM-IV, 1994) 4 in 1,000 (Bertrand et al., 2001). Data derived from the annual report of the Special Education Child Count (SECC; 1993-2000) indicated a 23% increase rate over a span of seven years of identified children (ages 6-21) spanning enrollment in 50 states, including the District of Columbia, public school systems (Shattuck, 2002a, 2002b). Jones (2006) considers educational interventions to be held by many to make a significant difference to the prognosis and well-being of a child or adolescent with an ASD. Are educational interventions focusing on the emotional regulation challenges an adolescent with HFA/AS faces related to the development of social communicative competence (Laurent et al., 2004)? The proposed research seeks to find some answers to this question, among others, especially in the light of what Farrell (2004) noted about a first year college student with autism who despite the ability to play every band instrument during his eighth grade at elementary school and achieving honors in his academic subjects he struggled in college to accomplish the most mundane of assignments. He was unable to seek out appropriate help. His literal-mindedness and inability to make inferences caused him to withdraw from the classes to avoid failing. Are adolescents with HFA/AS receiving information to help them build and utilize social relational and adaptive skills when faced anxiety provoking situations? What supports are available and consistent for persons with autism in high education?

Promoting Social Relational and Adaptive Skills for the Future

Building a repertoire of social and adaptive skills as well as an understanding of interrelationships are preparatory building blocks for future success in the general milieu of work and society. School based mental health professionals are in the position to provide such building blocks for those who find it difficult to assimilate such skills through cultural and adaptive behavior maturation. Researchers are in the position to explore and report on the process in action.

A briefing in the U.S. Senate in Washington, D.C. on March 21, 2006 sponsored by several counseling bodies including the School Social Work Association of America recognized the part school-based mental health service providers can play in the provision of support and services. What is not clear from the research literature is how much support or what type of services are being provided for adolescents with HFA/AS to address their needs with regards to improving their abilities to socialize as well as how they are managing to integrate into the world of their peers, e.g., What *are* the personal experiences of adolescents with HFA/AS? Is the extrapolation of any skills learned promoting an easier transition and acceptance into the social world of teen interaction?

The focus of this study is to explore the perceived social experiences of adolescents with High Functioning Autism (HFA) and/or Asperger's Syndrome (AS) between the ages of 12-18 years and the view of their caregivers of the social experiences and adaptive behavioral abilities of their adolescents with HFA/AS as well as the programs, intervention or services that have been experienced by the adolescent.

Interventions

Many of the interventions and services have been directed to and are specific for younger populations (Bondy & Frost 1994; Gray, 1994; Greenspan & Wider, 1998; Lovaas & Smith, 1989) and the importance of early intensive and pertinent intervention cannot be over emphasized. There are substantial amounts of information within the research literature covering the importance of early intervention, the quality and choice of interventions and outcomes as well as the possible etiologies of autism. However, although there is a burgeoning of information on adolescents with autism within the research literature there is a paucity of information regarding the services and interventions provided for these adolescents as they begin to navigate the social world of peer relationships, and embark upon the necessary acquisition of personal and self-sufficiency skills that will enable them to participate in the expanding world of socialization after childhood.

Early intervention with any disorder that is developmentally based is not only desirable but essential. Much has and is being done to address and provide services for infants and children with Autistic Spectrum Disorders. Programs such as “Treatment and Education of Autistic and Related Communication Handicapped Children Program” (TEACCH) (Schopler, Mesibov, & Hearsey, 1995; Steinhausen & Verhulst, 1999) and “Lovaas Applied Behavioral Analysis” (ABA) also known as the discrete-trial training (DTT) (Lovaas, 1981; Lovaas & Smith, 1989) continue to provide education and support for persons with autism along with relationally oriented and socially interactive programs

such as Greenspan's Floor Time (Greenspan & Weider, 1998) and Relationship Development Intervention (RDI) (Gutstein, 2000).

Autism is generally diagnosed in infancy, childhood or adolescence and is therefore seen as a developmental disorder. Lack of constancy as well as invariance in the development of an individual with autism necessitates on-going assessments and needs evaluation with concurrent validation as to whether interventions fall within good practice methodology.

The needs of adolescents with autism are the same as those of younger individuals with autism which center round communicational, behavioral and social relational issues (Mesibov & Schaffer 1986). Investigations into interventions that focus on the support services for adolescents with HFA/AS seem sparse within the research literature and the need for research based exploration that provides for greater clarity with respect to treatment and programming guidelines for adolescents is essential (Tsatsanis, Foley & Donehower, 2004). Developmental mental state attribution – the process of searching for the mental and intentional causes – in other words understanding social causality – becomes increasingly more complex with age. Simply put, it starts with low-level social perception during human infant development such as the infant's ability to follow his or her caregiver's eyes or gesture to an interesting object to the ability of an individual's development of an empathic understanding of another mind (Baron-Cohen et al., 2001). At both ends of this continuum of mental state development those on the autism spectrum suffer equally. It has already been mentioned that much is being done to assist in early

intervention for toddlers and children. What is not clear is the response to intervention for adolescents with HFA/AS.

Ground breaking behavioral interventions for persons with autism such as the TEACCH Program, which began in the early 1970s, was the first legally mandated state-wide program for children with autism and a mandate that was expanded to include adolescents and adults across their life time. One of the main principles of the TEACCH Program was to develop programs to help caregivers manage their children with autism at home. Families were seen as the pivotal piece in community-based care. The system also called for inclusion in regular public school classroom settings. Components were developed to address crisis management and sex education for the developmental changes that occur during maturation (Mesibov & Schopler, 1983). Due to an increase in services in the 1990s for high functioning adolescents with autism, groups for adolescents were implemented through the TEACCH Program to serve individuals who had limited social experiences outside of school. As the group process developed over time the group dynamics have been shaped, either directly or indirectly, by the teens themselves with a focus on belonging to a group and enjoying each other rather than practicing social skills per se. The youth want to feel competent in the areas of being a friend, playing games, expressing their creativity, and participating in the community (Marcus & Bianco, 2002; Siegel, 2003).

Koegel, Koegel, and McNerney (2001) reviewed research over the years, between the 1960s and late 1990s, to determine pivotal areas that influence interventions for autism. The article's focus is on lower functioning, and/or younger individuals with

autism; however, Koegel et al. consider children with autism are lacking fundamental skills crucial for life success such as motivation, self-management and self-initiations. How are adolescents with HFA/AS being helped to develop these pivotal and requisite qualities? Tsatsanis, Foley and Donehower (2004) acknowledge the surge of interest with regards to the needs of adolescents with HFA/AS but also emphasize the parallel need for empirically supported efficacy of programs targeting this population. Long-term outcome research for individuals with HFA/AS has shown that limitations in social communicative competence impede the processes of adapting to new social demands in both academic and community setting and the achievement of vocational goals later on in life (Gilchrist et al., 2001; Tantam, 2000; Tsatsanis, 2003).

Interventions for children and adolescents seem to fall into two arenas – educational and clinical. As mentioned earlier Catherine Lord (NIH, 2001) noted that some schools are still debating whether social development is part and parcel of general education. But as this debate may continue research indicates that both arenas are researching and implementing interventions even though the breadth of literature is narrower with regard for adolescents with HFA/AS.

Interventions that focus on intersubjective engagement such as Gutstein's Relationship Development Intervention (RDI) concentrates on promoting and enriching communicative engagement between the person with autism and his or her caregiver and/or peers with the underlying and important premise of enjoyment. RDI focuses on, among other things, specific variables in the communicative process: *referencing* or being able to base one's reactions on one's social partner's reactions; *reciprocity* – the

give and take part of a relationship; and *repair* the ability to process hurt or angry feelings that will inevitably arise in any relationship, and the ability to mend bridges or forgive (Gutstein & Sheely, 2002).

Relational interventions such as RDI usually fall outside of the realm of educational institutions. Evidence-based and peer reviews (Bryson, Rogers, & Fombonne, 2003; Darraj, 2005; Gabriels & Hill, 2002; Howlin, 1997; Tanguay, 2000) of the Lovaas-ABA method, TEACCH, and RDI interventions indicate a large body of literature on ABA – evidencing gains for younger children with autism in the areas of cognitive, adaptive, behavioral and communicative skills; relatively smaller peer-reviewed literature on the TEACCH program with indications of improved behavior, compliance, cognitive, and communication skills and only two controlled studies for RDI where data indicates a high percentage of improvement for children participating in the RDI program over children not participating in the program (Gutstein, Burgess & Montfort, 2007; Gutstein & Tyler, 2002). Tanguay (2000) considers that as interventions couched in either discrete-trial learning or social-pragmatic therapies have evolved there has been a subtle mingling of the varying techniques from both interventions in the application of practice. He also notes there is no one treatment for everyone and that treatment may need to be continued in one form or another on into adulthood as is described in Project TEACCH.

Research articles in the realm of education indicate that educators are looking beyond the mandate of IDEA 2004 (Smith & Slattery, 1993) to promote successful inclusion practices and strategies aimed at increasing social interactions (Safran, 2002;

Villa et al., 2005; Welton et al., 2004). Recognizing the unique characteristics, vulnerabilities and varying levels of abilities presented by adolescents with HFA/AS are key components to providing appropriate instruction and supports (Miles & Simpson, 2001).

The questions here, for this particular study, are:

- (1) What treatment/ interventions are being carried over from early childhood on into middle school and beyond, or established at some point during this time, for adolescents with HFA/AS?
- (2) Are these interventions addressing the processes of social relational experiences and promotion of adequate adaptive behaviors for establishing a connection with same age peers?
- (3) What are the similarities or differences between parent and adolescent prospective regarding any interventions tried?
- (4) What are the similarities or differences between parent and adolescent prospective regarding social relationships?

Even though one treatment does not-fit-all the possible discovery of a thread that connects one social/adaptive oriented program to another would certainly be an essential one for the promotion of best practices. Or as Tsatsanis et al. (2004) state:

... one of the clear guiding principles that can be derived from current outcome research is the notion that appropriate educational opportunities and support services should be secured early, even in the face of more subtle deficits. Likewise, there is a clear need for intervention to focus on enhancing social communicative competence as well as adaptive functioning (p. 251).

Trajectory of Development for Individuals with HFA/AS

Clinical research on the continuity of care and understanding the trajectory of development for individuals with HFA/AS from childhood to adolescence is beginning to emerge in the literature. The Vineland Adaptive Behavior Scales (VABS) (Sparrow et al. 1984, 2005) has been used in several studies as a standardized measurement to help in determining implication for research, assessments and interventions (Bildt et al., 2005; Carter et al., 1998; Freeman et al., 1999; Gillham et al., 2000; Klin et al., 2005). VABS assess a person's *current* adaptive behavior through four domains; Communication, Daily Living Skills, Socialization, and Motor Skills, and the scales provide and can be compared to adaptive behavior across the developmental lifespan of individuals from birth through adulthood.

Adaptive behavior assessments highlight the strengths and weaknesses of an individual. Adaptive behavior is variable and can become worse or improve depending on interventions, changes in environment as well as physical or emotional trauma. It is defined by typical performance rather than ability. When considering "...the puzzling composite of strengths and weaknesses that is autism" as mentioned earlier from Sigman and Capps statement (1997, p. 27) the incorporation of questions that target adaptive behaviors are seen as important in the investigation of social experiences for those with HFA/AS.

Freeman, Del'Homme, Guthrie, and Zhang (1999) used the Vineland as a tool for measuring "change in individuals with autistic disorder as a function of both age and initial IQ." In recognizing several methodological limitations, Freeman et al. results

indicate "... support for the position that the primary focus of treatment should [be on] functional social communication skills."

Klin, Pauls, Schultz, and Volkmar (2005) incorporated the Vineland as a standard procedure to highlight the social disability of HFA/AS adolescents and young adults in a study where the object was to examine the implications of three alternative definitions for AS.

Gillham, Carter, Volkmar and Sparrow (2000) used it as a diagnostic tool providing information on a person's appropriate age functions within the domains of communication, socialization and other relative behaviors. Their results show an agreement with other studies where "the argument that impairment in socialization is more central to autism than the presence of unusual or deviant behaviors." Additionally, children with autism in this study demonstrated substantial delays in socialization relative to their chronological and mental ages falling 3.5 or more standard deviations below the normative sample mean. Concerns in this study as to whether certain items in the addition of the Vineland used were good enough determinants to distinguish children with a Pervasive Developmental Disorder-Not Otherwise Specified (PDDNOS) from children with other developmental disorders – plus previous reflections on the greater intradomain scattering of children with autism compared to either typically functioning children or children with mental retardation (Carter, Volkmar, Sparrow, Wang, Lord, Dawson, Fombonne, Loveland, Mesibov, & Schopler 1998) seems to have preempted a second edition of the Vineland – the Vineland-II – which specifically targets the social

skills of children, adolescents and adults with autism spectrum disorders (ASD) among other disorders (Sparrow et al., 2005).

With these studies in mind questions regarding social skills and relationships based on questions appearing in the Vineland-II Adaptive Behavior Scales domains of Communication; Living in the Community; and Social Skills and Relationships will be incorporated into the interview questions of both the parent/ caregiver and adolescent with HFA/AS. The rationale behind selecting only a few of the questions rather than administering the complete rating form is to (a) use questions in the interview that have their basis in valid and reliable material; (b) are pertinent to the study at hand; and (c) reduce the time and effort required for a parent/caregiver subject who will be asked to complete a video-taped interview and a lengthy questionnaire.

Additionally, within the context of neuropsychological testing and/or assessment for admission into special education or for reevaluation while in special education the Vineland (or any other standardized adaptive measure of choice of the examiner) is an essential part of the profile of the student and adds to the holistic view of the student (Gabriels et al., 2002).

Prognosis – A Window into the Need for Research on Adolescent Autism

Klin (1996) in a paper presented at an international conference stated that educational curriculum and treatment strategy “involves the need to enhance communication and social competence.” He went on to say, “... individuals with AS are not loners by choice, and ... later on they may become despondent, negativistic, or even

clinically depressed as a result of their increasing awareness of personal inadequacy in social situations” (p. 16).

A longitudinal follow-up study by Billstedt, Gillberg and Gillberg (2005) of 120 individuals with autism who were followed prospectively for a period 13-22 years and reevaluated at ages 13-40 years took some of the “may become” out of the speculation of what becomes of persons with autism. Using various instruments to measure for communication, psychiatric health, adaptive behavior and employment, Billstedt et al. found that “...38% had had a remarkably problem-free adolescent period. However, 31% had shown major problems and more than half of these had deteriorated significantly in puberty. Thus, altogether 17% of the 108 examined were reported to have had a clear set-back in puberty and half of these never really recovered.” (p. 357). Although IQ was a strong predictor of outcome in this study where the lower the IQ the poorer the outcome Billstedt et al. noted that even for the individuals with higher IQ the outcome was relatively poor. *Good outcome* was defined as being employed, or in high education/vocational training, *and* if over the age of 23 years, living independently, if 22 years or younger, having two or more friends/a steady relationship. No specific definition was given for relatively poor outcome. However, the definition *Restricted but acceptable outcome* made reference to a group of people with the characteristics of poor outcome but who have been accepted by a group of peers or personnel to such an extent that their handicaps are not so readily obvious. *Poor outcome* demonstrated obvious handicap, no independent social progress and some clear verbal or non-verbal communicative skills (p.

354). Within this study there was no reference or indication of any interventions experienced by the persons with autism.

In an article by Szatmari et al. (2003) IQ level was also considered as a predictor of better outcomes for persons with autism. The objective of this study was to assess the extent to which measures of nonverbal and language skills affected children/ preadolescents with AS over a span of four years. The clinical implication of this study was that early language and nonverbal skills were important predictors of outcome in communicative and social competence domains determined from the Vineland Adaptive Behavior Scales (Sparrow et al., 1984). However, the authors cautioned that focusing on language alone may not have “significant impact on social skills, on autistic symptoms or on outcome of children with AS” (p. 527), and that it was important for parents to grasp the concept of varying achievement abilities across multiple domains.

In the above mentioned studies reference to parents was not necessarily a keystone aspect but certainly an important one. Parents taking part in Billstedt et al. (2005) study recollected a “... fairly uneventful, ‘easy’ adolescent period ...” for their child/adolescent/adult with autism. The exact number of parent reporting this was not mentioned; however, “Slightly under one in five of all typical/atypical autism cases deteriorated in adolescence, a deterioration that appeared to be permanent in 50% of the cases” (p. 358). Szatmari et al. (2003) considered the importance of keeping parents informed about outcomes and programs. Parents of older children with autism have passed through the initial phase of understanding their child’s diagnosis and are now

facing concerns about finding services that will enhance and support their child's development over his or her lifetime.

Caregivers/Parents

It is only natural for parents to grieve over the loss of a potential normal life for their child once the child has a diagnosis of HFA/AS. Through retrospective case studies using qualitative research methodology such as the one completed by Krausz and Meszaros (2005) where a mother describes 18 years of parenting a child with autism to anecdotal reports in books specializing in information for providers and parent of children with autism it is apparent that feelings of loss and sadness ebb and flow across time and vary in intensity across developmental stages (Exkorn, 2005; Siegel, 2003).

“There is no question but that experiencing AS from the inside out, as our children do, can probably never be fully understood by those of us on the outside peering in no matter how well we know or how deeply we love them” (Romanowski et al., 2005, p. 131).

This statement holds in it the importance of hearing the perspectives of the individual with HFA/AS as well as that of his or her parent in the search to not only improve our view from the outside but to also determine how interventions and supports are perceived by the individual with HFA/AS.

Overton and Rausch (2002) gathered together a total of eleven mothers with children with disabilities to discuss their experiences and concerns. Mother's whose children were on the autistic spectrum expressed the same and similar concerns as mothers of children with other disabilities. Developing and having relationships at all levels of cohesiveness from casual to best of friends was seen as the catalyst for healthy

development and well-being. The mothers wanted their children to gain skills that would enable them to take responsibility for their own peer relationships but they also wanted their children to be safe in the process and not be bullied, ridiculed, or fall in with the wrong crowd. All mothers expressed a high level of involvement in their children's social life because their offspring were unskilled in the process of making and keeping friends. The mothers did not want to be so involved but expressed the belief that no one else was addressing these needs.

The Adolescent with HFA/AS

Bauminger and Kasari (2000) conducted a study to examine the conception and understanding of loneliness and friendship as reported by children with HFA compared to normally developing peers. The age span for the groups was between 8 and 14. The findings of the study indicate that children with HFA have the desire to form social relationships with others and understood the meaning of friendship. However, they were unable to connect the concepts of friendship and loneliness whereby having a friend could reduce feelings of loneliness. This connection was made by the normally developing children in the study. The mothers of the children with HFA also were asked to report their perceptions on the friendships experienced by their children. The children were asked to complete a questionnaire about their thoughts. The comparison of mother/child reports yielded significant differences. "Mother's reports of their children's number of friends ($M=2.3$) were greater than their children's reports ($M=1.6$)" (p. 451). General themes extrapolated from the mothers' reports were that mothers frequently described desired relationships rather than actual relationships. Also, the idea of "playing" with

others was watching videos or playing video games. Friends tended to be from special education or in a few cases a friend was a relative.

Another article by Bauminger (2002) focused on the unique social-emotional characteristics of “children with autism who have normal intelligence” (p. 283). The ability of individuals with HFA to engage in a higher level of social relationships because of their normal intelligence compared to children with autism classed as low-functioning – those with mental retardation – can present as a double edged sword. According to this study individuals with HFA desire social contact with their peers and when this does not pan out persons with HFA express loneliness and depression in the absence of such relationships. The probability of a person with autism developing symptoms of depression has been touched upon in the literature spanning the past three decades with implications for adolescents with HFA/AS scant but appearing in more recent years (Barnhill et al., 2001; Ghaziuddin et al., 2002; Hedley, 2006; Hill et al., 2004; Meyer et al., 2006; Wing, 1981).

The abatement, resurgence and emergence of symptoms within the context of autism continues to be an enigma in and of itself with studies where parents mention fewer symptoms and improved adaptive behavior, with the exception of communicative skills, during adolescence and early adulthood (McGovern & Sigman, 2005); improved ability in adolescents to relate to adults but continuing difficulties with same aged peers (Orsmond et al., 2004), and development of comorbid conditions such as anxiety (Farrugia & Hudson, 2006).

Interviews with adolescents with AS, such as those conducted in a study completed by Marks, Schrader, Longaker, and Levine (2000) focused on students' perceptions of their disability, and their school experience. The intention was to gather descriptive data from five subjects to promote a more insightful view and understanding of aspects of the subjects' world. Out of five students designated for the interviews only three were interviewed. At the time of the interview one of the subjects chosen was unwilling to participate, and one had been hospitalized due to emotional distress. The three subjects interviewed all did well academically. Despite the presentation of three different personalities all wanted, but seemed incapable of developing, a friendship base. The three adolescents (all male) aged 13, 15, and 15 were diagnosed with an ASD at the ages of ten (school diagnosis at age 4), three (age 13 changed from PDD to Asperger's Syndrome), and three (diagnosed with autism at 3), respectively. Parents of one subject considered their son fit diagnosis of Asperger's Syndrome when he was in fifth grade. The eligibility category for the Individual Education Plan (IEP) was changed to reflect this. The complexities emerging from this study regarding diagnoses, experiences in beginning grades, and transitions into middle school reflect many of the aforementioned studies. It was reported that understanding and positive teacher/peer attitudes as well as early childhood educational programs helped made for happier classroom experiences in the lower grades. However, as these particular subjects entered adolescence social acceptance and support seemed to take a down turn as the adolescences' interest took on a more mature interest in learning how to interact and communicate more effectively.

The number of subjects with autism in Bauminger and Kasari's study (2000) was 22. The sample size of subjects with autism in the SEELS report mentioned in the earlier part of the literature review was 1,064. The number of interviews in Marks et al. (2000) study was three. However, the outcomes appear to be very much the same – friendlessness, isolation, and loneliness. It is not clear whether these sad conclusions were reached despite a series of supports and interventions tried across the developmental life thus far of individuals with HFA/AS in the study. Investigation into age-related changes in social relationships, particularly through adulthood are few (Orsmond et al., 2004), and little is known about the long-term outcome of autism (Billstedt et al., 2005). The ultimate goal of this research is to explore the social relationship of adolescents with HFA/AS and to expand upon the knowledge base of adolescent autism for the promotion of best practice.

Summary

Autism is a life-long developmental disability, and as such requires appropriate interventions across the life-span for individuals who suffer from this disorder. Since Kanner and Asperger, the fathers of autism, made the first observations of their young patients back in the 1940s the diagnosis of Autism has emerged as one of the most commonly occurring disorders in pediatrics. As a developmental disorder it interferes with the normal development and socially transitional processes of growing children. The core criteria for autism or what sometimes is known as the triad of impairments: qualitative impairment in social interaction; qualitative impairment in communication; restricted repetitive and stereotyped patterns of behavior, interests and activities show

strong stability over time and most children diagnosed with the disorder continue to meet the criteria as adolescents and young adults even though some of the symptoms may decrease in severity.

Since its inclusion in the list of disabilities under IDEA (1990 amendments), autism's cumulative growth rate is reported as skyrocketing from an initial 22% to 805%. Possible reasons for this increase have been discussed in the literature and include changes in diagnostic criteria, development of an autistic spectrum, as well as growing knowledge among professionals and parents. Additionally, complex genetic factors are being considered as playing a major role in autism's etiology (Fombonne et al., 2001; Mandell et al., 2005; Wing, 2005; Wing & Potter, 2002).

Seventy-five percent of individuals who suffer from autism are mentally retarded. The remaining twenty-five percent have average to above average IQs and are most commonly known as individuals with high functioning autism (HFA) or Asperger's Syndrome (AS). The population of interest for this study is adolescents with HFA/AS between the ages of twelve and nineteen for the following reasons: paucity of information in the literature pertaining to interventions and supports for adolescents with HFA/AS, more similarities than differences between HFA/AS regarding significant difficulties in social understanding and social relationships, caregiver/parental concerns regarding their adolescent's adaptive functioning and place within the social relational world, and the need to listen to the voice of the adolescent with HFA/AS.

There are substantial amounts of information within the research literature covering the importance of early intervention, the quality and choice of interventions and

outcomes as well as the possible etiologies of autism. However, there seems to be a paucity of information within the research literature regarding the services and interventions provided for adolescents with HFA/AS as they begin to navigate the social world of peer relationships and embark upon the necessary acquisition of personal and self-sufficiency skills that will enable them to participate in the expanding world of society after child and adolescent hood.

Although time spent at school only counts for a portion of the waking hours for all students, it is during this time that appropriate interventions can be practiced for students with disabilities such as autism. School is the place where peers interact with each other, and friendships can be forged. Large and small scale research into social time spent outside of school reveals that children/adolescents with autism in general are friendless, lonely, and isolated compared to cohorts who have or do not have a disability.

The needs of adolescents with autism are the same as those of younger individuals with autism which center around communicational, behavioral, and social relationship issues. Reports from caregivers confirm this, and the voices of the children and adolescents themselves with HFA/AS tell us that they want friendship but seem to have a difficult time understanding what friendship is and the feelings that go along with this most basic but complex necessary connection between one human being and another.

The key predictors for more positive outcomes for individuals with HFA/AS as they progress along their developmental path are average to above IQ and early interventions. It is extremely important a continuity of interventions and supports continue throughout the life-span of persons with HFA/AS due to their propensity to be

loners and their difficulty in processing and understanding social relationships. Personal reports from mothers in one study mentioned here indicate a belief in lack of professional support and education with regards to providing the tools and skills for their children to negotiate *social relationships*. As far back as 1983, Fredericks et al., were questioning whether in the process of limiting environmental stimuli to accommodate for the idiosyncrasies of the student with autism, with the object of enhancing educational and training objectives, the student(s) with autism may no longer relate to his or her *functional* environment. This seems a question still unanswered.

Adaptive behavior assessments highlight the strengths and weaknesses of an individual and are excellent resources for tracking progress as well as tools for providing best practice interventions. The Vineland-II Adaptive Behavior Scales has been used in many autism driven research studies and its recent revision has increased its pertinence for establishing a person's current adaptive behaviors in domains that are akin to the triad of impairments: communication, daily living skills and socialization.

There are three main focal points in this study – one to record and listen to the voices of adolescents with HFA/AS as they negotiate and participate in social life – two to establish some understanding of the adolescents' relational adaptive behaviors; and three to compare the voices of the adolescent him or herself and that of their parent/caregivers as they all negotiate the world of interventions and supports for those with a diagnosis of HFA/AS. Although research reviewed has covered these areas in one form or another none were found that addressed all three areas in the manner of data collection intended for this study.

CHAPTER II

METHODOLOGY

Research Design and Introduction

This study followed an exploratory qualitative data design using a Grounded Theory approach. Broad categories were determined from responses to open-ended questions through independent face-to-face interviews with the adolescent and the parent/caregiver. Sub-themes from these broad categories elaborated on the topography of meaning expressed by the participating subjects (Glaser & Strauss, 1967; Creswell et al., 2003; Crossman et al., 2003). Data for this research was collected through three different sources: (1) a questionnaire completed by the parent/caregiver designed by the researcher incorporating demographic and closed-ended questions. (2) Videotaped interview with parent/caregiver that included open-ended questions that targeted three areas of interest: diagnosis of HFA/AS, the social experiences from the perspective of the parent/caregiver, and questions that explored current adaptive behaviors of adolescent as viewed by the parent/guardian (see Appendix F). (3) Videotaped interview with the adolescent with HFA/AS that entailed corresponding interview questions used for the parent/guardian interview (see Appendix H).

Sample Population

The study population was a convenience sample of seven (7) adolescents between the ages of fifteen (15) and nineteen (19) with HFA/AS and a corresponding caregiver for each adolescent making a total subject pool of fourteen (14) subject participants. The definition for HFA/AS was an adolescent with an IQ of at least seventy-five (75) placing them within the average range of intelligence and/or above who has received a diagnosis on the Autism Spectrum Disorder through clinical or school based assessment as reported by a parent/caregiver. In other words, the adolescent subjects were recognized as falling within the spectrum of autistic disorders indicating High Functioning Autism (HFA) or Asperger's Syndrome (AS). According to Newschaffer, Fallin and Lee (2002):

Autism spectrum disorders (ASDs) are developmental disabilities where language development is absent or delayed, rote or repetitive behaviors typically emerge, and nonverbal communication, imagination and social interaction are profoundly hindered (1). The severity of impairment in each dimension can be quite variable, as can individual cognitive functioning. (2) However, even high-functioning persons with ASD are confronted with significant lifelong challenges (p. 137).

Newschaffer et al. also note that the concept of “spectrum” allows for a continuum of impairment which may also extend outside clinical bounds to those with combinations of milder social abnormalities and communication impairments and less rigid interest restrictions.

Sample Recruitment

The convenience sample was recruited from within the researcher's catchment area of Northern Illinois and included clinical subjects from the University of Illinois, College of Medicine, Rockford, Illinois, where the researcher is a staff/faculty member and therapist. The method for acquiring the number of needed subjects was as follows:

Recruitment letters were sent out to the clinical subjects (see Appendix A). In addition the intent was to visit a parent support group and during this meeting, after giving a brief introduction and reason for the visit, to hand out recruitment letters (see Appendix B). However, after several phone calls and emails, the meeting did not materialize. The contact person/manager for the parent group, after listening to a description regarding the research, asked for the recruitment letter to be sent for her review. A stamped addressed envelope was included for the return of the signed recruitment letter which would indicate an interest in participating in the study.

On receipt of a returned recruitment letter the prospective subject was sent a "Consent to Participate in Research" to Parent/Caregiver (see Appendix C) and an Assent letter for the Adolescent (see Appendix D) and a Health Insurance Portability and Accountability Act (HIPAA) Authorization to use Private Health Information (PHI) (see Appendix E). The contents of this correspondence followed the format as required by the IRB and included explanation of Purpose, Procedures, Risks/Benefits, and Voluntary Participation and a comprehensive explanation of Confidentiality. The assent letter was scribed at a reading level for persons reading at a sixth grade level or above (see Appendix E).

A stamped addressed return envelope and two copies of consent and assent letters and HIPAA Authorization letter were provided: one set to be signed and returned to the researcher and one set to be kept by prospective subjects for their records (see Appendix C). On receipt of signed consent and assent from the parent/caregiver and adolescent the parent/caregiver was contacted via phone with a follow-up email confirmation where applicable to acknowledge the receipt of the forms and to set up a convenient time and place for the video-taped interview. Via telephone communication and/or email a time was set up for the interview of the adolescent either individually or with parent present according to the comfort level of the adolescent and/or his or her parent. Each adolescent consented to be interviewed alone. Arrangements were made with the participants to meet in a safe, private, and convenient place at a mutually agreed upon time. The adolescent interview and separate parent/guardian interview was a videotaped recording that lasted no longer than thirty minutes. Time was taken before and after the adolescent interview to assess the comfort level of the adolescent and explain the interview process and to address any concerns or stress the adolescent may have experienced. Additionally, time was taken to assure the comfort level of the parent/caregiver.

In consideration for confidentiality each family who agreed to participate in the research was assigned a number and this number was used as identification on the questionnaire and videotaped interview.

Instruments and Data Collection

Six of the seven parent participants completed a parent/caregiver questionnaire constructed by the researcher (see Appendix F). The parent/caregiver questionnaire consisted of close-ended questions covering general demography, diagnosis and pharmacology, clinical and school based interventions, and choice of educational setting. As this questionnaire was produced by the researcher reliability and validity cannot be established. However, as a pilot, the questionnaire was given to two parents of an adolescent with HFA for completion and suggestions and comments regarding the content were taken into consideration for the format and content of the final questionnaire.

The semi-structured videotaped interviews included questions pertaining to the adolescent's adaptive behaviors regarding daily living skills, socialization at home and school as well as within the community. Along with adaptive behavior questions the semi-structured interview included questions pertaining to the parent/caregiver, and adolescent thoughts on interpersonal and social experiences (see Appendix G1 and Appendix G2).

Data Storage and Data Analysis

All data for the research was stored in a manner to maintain the confidentiality of the subject participants. Each questionnaire and videotaped interview was identified through a number allocated to paired parent/adolescent subjects. Identifying information was kept separately from the numbered information. Data information was stored on flash drives which were kept under lock and key as were the videotaped DVDs.

The conceptual framework used for the analysis of data was Grounded Theory (Glaser & Strauss, 1967; Strauss & Corbin, 1998) and the focus of this research was to gain an understanding of the social experiences of adolescents with HFA/AS through their verbal report and the perceptions of the adolescent's parent/caregiver. As per Grounded Theory the first recorded interview was transcribed and read through several times for the purpose of recognizing and noting prominent features or themes within the content. As subsequent interviews were read the object of analysis was to verify the reoccurrence of these themes or to detect new ones. The purpose of this process was to delineated information from the spoken responses of the subject participant while still, as much as possible, retaining the integrity of the story shared by the interviewee. These themes and patterns provided an organizational structure through which individual experiences merged into collective phenomenon experienced by all. Interpretation of the meaning of the interviews was put forth by the researcher within the context of experience in the field and current literature (Rossman & Rallis, 2003).

Delimitations and Limitations

This study was confined to the subject population of adolescents with HFA/AS and data collection from two sources - the adolescent himself or herself and the corresponding parent/caregiver. The choice of a convenience sample recruited from within the researcher's catchment area of Northern Illinois limited and/or impeded the ability to generalize the results to other communities. The collection of data through face-to-face interviews comprising of open-ended questions were put to parent/caregivers and their adolescents plus a questionnaire answered by parent/caregiver interviewees

excluded the possibility of a third party response, such as a teacher. This third party could have given a different perspective from outside of the family circle. Additionally, the very process of being videotaped and interviewed and/or writing down answers, both processes controlled by the researcher, may have encouraged or increased the chance of the phenomena of “social desirability” with regard to the parent/caregiver responses. In addition, the idiosyncratic behaviors and core deficits of persons with autism may have caused difficulties in gaining rapport with the adolescent interviewees (Creswell, 2003).

Feasibility and Rationale

Despite delimitations and limitations that come with any research endeavor the feasibility of this study lays not only in the reported increase in persons with HFA/AS but also in the rationale to add to current information on the social experience of an adolescent with HFA/AS as he or she is in the process of transitioning from childhood to adolescent-hood and beyond. Information gathered through this research verified and/or added to aspects in the current literature and research on adolescents with HFA/AS. The opportunity afforded to the adolescent and his or her parent/caregiver to speak for him or her self regarding the diagnosis of HFA/AS and its ramifications helped to highlight the social and adaptive experiences in a personal way as well as gathering the essence of what it is like to be an adolescent with such a disability. Results from this research provided information that may help in the development of supportive interventions to diminish the isolation of adolescents and young adults with HFA/AS. In addition the results may promote a better understanding by professionals involved in the care of

adolescents and/or young adults with HFA/AS of the psychosocial experiences or lack thereof of such adolescents and young adults.

CHAPTER III

RESULTS

Framing

As noted earlier, the design of this study employed the qualitative method of grounded theory. Grounded Theory is based on inductive rather than deductive logic. As such findings or results are emergent from data as they are concurrently collected and analyzed.

A key component of grounded theory is theoretical sampling. Glaser and Strauss (1967) described theoretical sampling as an iterative process that has the goal of developing a rich understanding of the dimensions of the research focus. In practical terms theoretical sampling translates into the initial collection and analysis of two sampling events. An initial case is selected and, on the basis of the data analysis pertaining on that case resulting in the articulation of an emerging theory, additional cases are collected and analyzed.

During initial data collection, as main concepts emerge, full and deep analyses of the data are necessary. As data collection and analyses continues, theoretical sampling continues until theoretical *saturation* occurs. According to Glaser and Strauss (1967) saturation occurs when no additional constructs are emergent from the data. Once theoretical saturation has been reached, data collected is terminated.

When engaging the method of theoretical sampling the researcher makes a commitment to being the ultimate story teller of the stories shared by the subjects in his or her research (Geertz, 1983; Moustakas, 1994; Rossman & Rallis, 2003; Strauss & Corbin, 1990).

Use of Ground Theory Method in this Research

This research project began with the expectation that fifteen (15) parent - HFA/AS adolescent pairs would be recruited. After seven pairs had been interviewed the researcher reached a saturation point of emergent themes and sub-themes and the collection of data was terminated. With attention re-focused on writing up the results.

The themes and sub-themes gleaned from this research came from separate face-to-face video-taped interviews with the adolescent and his or her parent. These themes and sub-themes were strengthened through the physical presentation of the adolescent as observed during the interview by the researcher as well as parents' affect during the conversation. The physical manifestations of persons with autism, although not noted as a diagnostic requirement in the DSM-IV-TR (2000), are an integral part of a person with autism social presentation (Frith, 1989, 1991; Wing, 2005; Wing & Potter, 2002. In addition, analysis of the completed parent/caregiver questionnaire (see Appendix F), have been integrated into the results.

Emergent Themes

Emergent themes stemming from the compare and contrast of the parent and adolescent interviews establish connection and disconnection between the parent and adolescent interviews. These themes focus around the subjects of the diagnosis of HFA/AS, social interactions, both interpersonal and communal, and considerations of adaptive behavior within the context of home and society.

Themes running through the conversations of the parents regarding the diagnosis of HFA/AS were: *rejection, feeling blamed, emotional toll, and management of the disorder*. Themes emergent when discussing the diagnosis with the adolescents: *indifference; use of third person – plural and singular referring only to parents comments or ‘they’ references regarding the diagnosis of HFA/AS*. These responses gave the impression that the adolescents were distancing themselves from diagnosis of HFA/AS even though four out of the seven adolescents shared considerations of the positives and negatives of HFA/AS.

Crossover or similar themes from both the parental and adolescent interviews regarding social interactions were: *restricted social circle, object-oriented connections - rather than emotional ties, isolation - both self-chosen and imposed, and outsider*.

Within the context of the discussion regarding the adolescents’ adaptive abilities the emergent themes from the parents were: *lack of independence, lack of vicarious learning and developmental delays, and reliance on mother*. The adolescents were united in the *fear of driving a car* and the responsibility that goes along with it. For all

adolescents the management of day-to-day chores was an emerging experience where mother's support was a key factor.

Pattern of Emergent Themes

When comparing and contrasting parent and adolescent interviews, observations, and questionnaires a cohesive pattern of parent/adolescent support and need emerged with threads of anxiety, challenge and hope.

A pattern common to all parents who participated in the study was that past concerns were mellowed for each parent due to their adolescent's current progress. Nevertheless, uncertainties highlighted the future.

Experience of Diagnosis of HFA/AS

The Parents

To begin the interview with the parents I asked the parents to talk about their experiences of having a child with HFA/AS. Each parent's experience was similar in expressing the experiences of feeling blamed, disbelief, rejection, and the management of the diagnosis, and the emotional toll associated with having a child with HFA/AS.

Feeling Blamed. Early on in their child's development all parents were concerned about their respective child's development and behaviors. Two of the parents did not mention any negative experiences when seeking professional help to assess concerns regarding their child's development but five did. The five parents recalled statements such as: "you are over reacting" or "... an inexperienced first time parent," and/or being seen as over protective. Each came away from her meeting with medical professionals with a general feeling of incompetence. Mother's of children with autism in

the late sixties were labeled “refrigerator mothers” for their purported frigid interaction with their children (Bettleheim, 1972; Kanner, 1943). Although the idea of frigid mothers and the link between this and the cause of autism has faded with time, and the fact that the children in this particular study had not yet been diagnosed with HFA/AS, the parents perceptions were they were viewed as being at fault. One parent shared she was blamed by school personnel for failing to socialize her child correctly even though she was sending him to a social skills group. Another parent was criticized by family members for over-socializing and/or stimulating her child with too many extracurricular activities. Subsequently, she was blamed for pulling him out of the activities and thereby isolating him. The parent commented the activities were a disaster and also too difficult for her son to manage. Further discussion with the parent revealed that she was doing all the work while others observed and commented on her son’s behaviors.

One parent recalled a friend saying; “There’s no way he could be *that* difficult.” But after volunteering to watch the child for between four and six hours, when he six months old, the friend stated she would never watch him again.

The rejection by friends, family and school professionals regarding the clinical emotional presentations of the children was another hurdle for the parents to manage. Older family members, and elders in a particular church community considered the best way to manage such behaviors was a good spanking.

Rejection. The fear of rejection from both the parent’s point of view and that of others was a burden for all parents. One parent was so afraid her child would be “kicked” out of pre-school or harmed because of his behaviors did not try to send him to one.

Fortunately, in her case the family was supportive and took turns to look after him while she went to work. With regards to the other parents, they all managed alone. One parent said she did not seek help from extended family because of philosophical differences in child rearing.

Parents who put their children through Special Education, six out of the seven adolescents, spoke of rejection within this setting. A principal at one school initially thought a diagnosis of AS was ridiculous. One acute feeling of rejection stemmed from exasperation for one parent through a therapist's admission that the parent's child was "just a really tough case", and could not be helped anymore. This was the catalyst for the parents to consider a residential placement for their son. This consideration caused the parent to feel that she was rejecting her own son which was more unbearable than experiencing the rejection of others.

Management of the diagnosis. As each parent shared the process of managing a child/adolescent with HFA/AS their affect changed. Their voices became more pressured. Two parents were matter of fact in their presentation, and one fought back tears. Two parents stated they did not think the outside world really appreciated how difficult it was to manage a child/adolescent with autism. One parent likened it to having a second fulltime job, and all parents agreed there were so many things a parent needed to do such as educating herself about the supports and interventions for persons with autism, continuous follow-up on either concerns for her child or the child's programs, and never making the assumption her child learned by example.

The parent questionnaire (see Appendix F and Appendix I) contained a section on various therapies and interventions available for persons with autism. These therapies and interventions were selected as they were either programs covered extensively in the literature on autism or services available within the school system.

Six out of the seven parents completed and returned the questionnaire. However, discussion during the interview with the parent who did not complete the questionnaire confirmed the date of diagnosis for her child as nine years old by a psychiatrist (see Chart 1), educational placement in a public school in special education (see charts below), and her son's past intermittent participation in individual therapy and group therapy (see charts on pages 54 and 56) which corresponded to the following information presented in chart form regarding the six parents who completed the questionnaire.

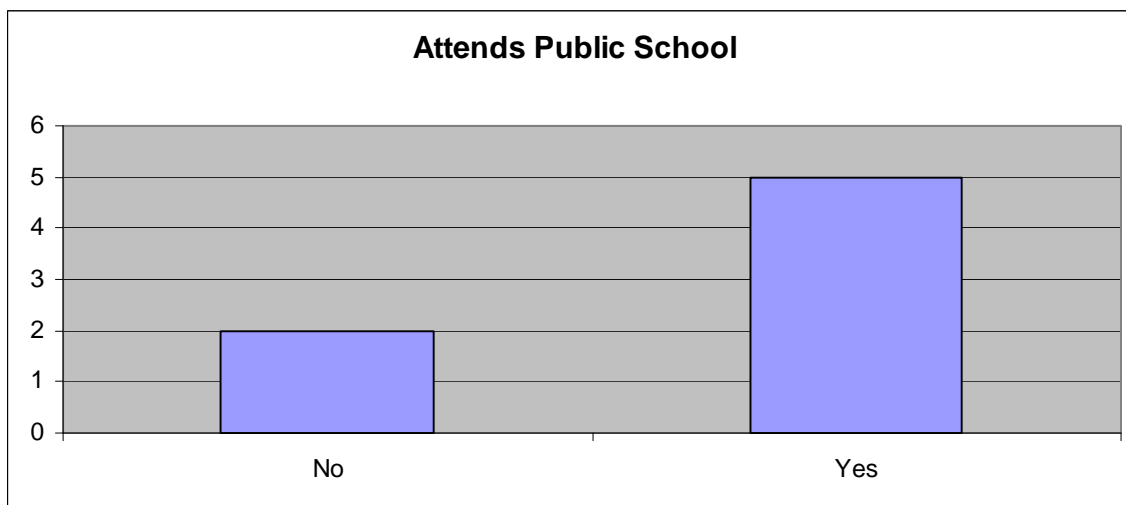


Chart 1. Question #35: Attends Public School

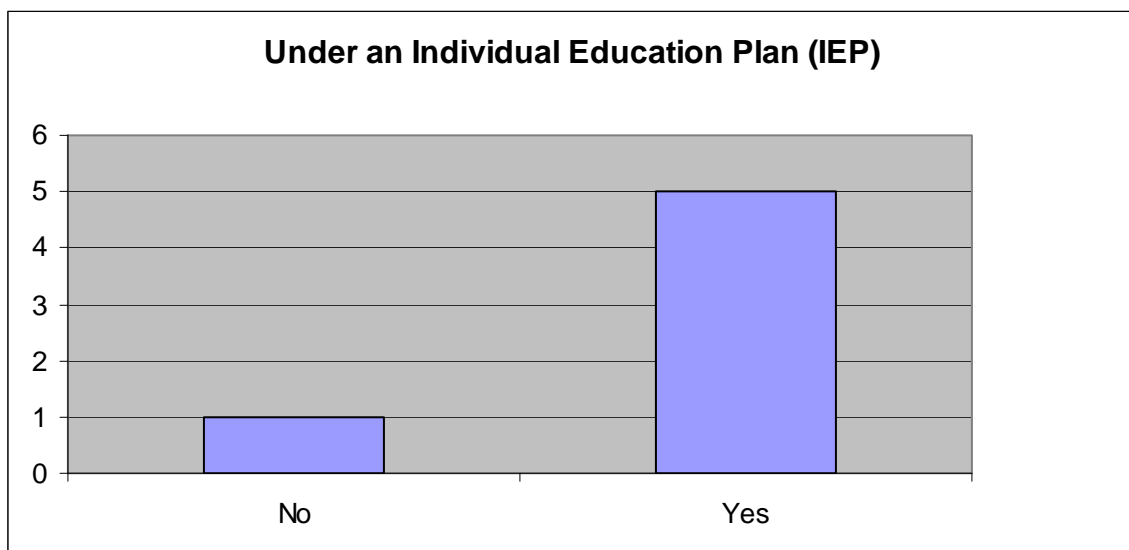


Chart 2. Question #36: Under an Individual Education Plan (IEP)

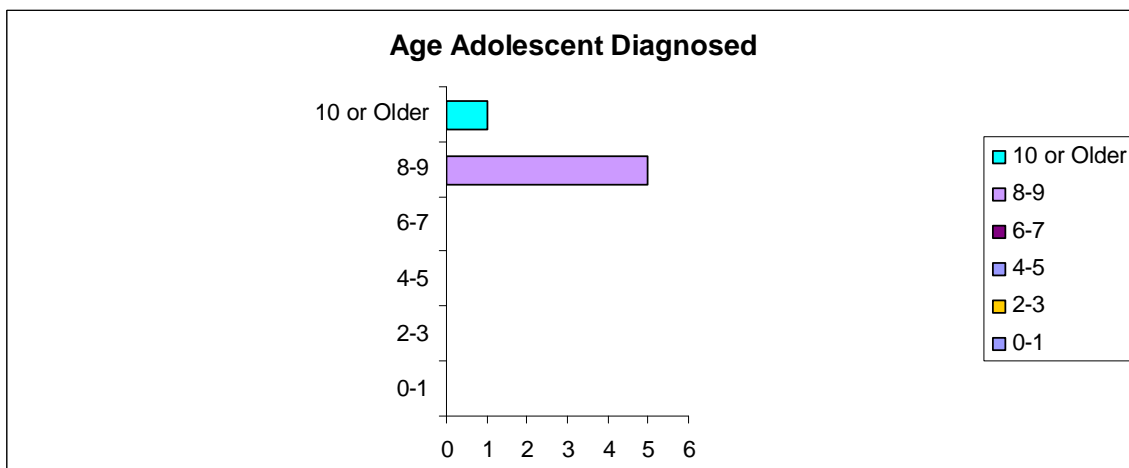


Chart 3. Question #15: Age Adolescent Diagnosed

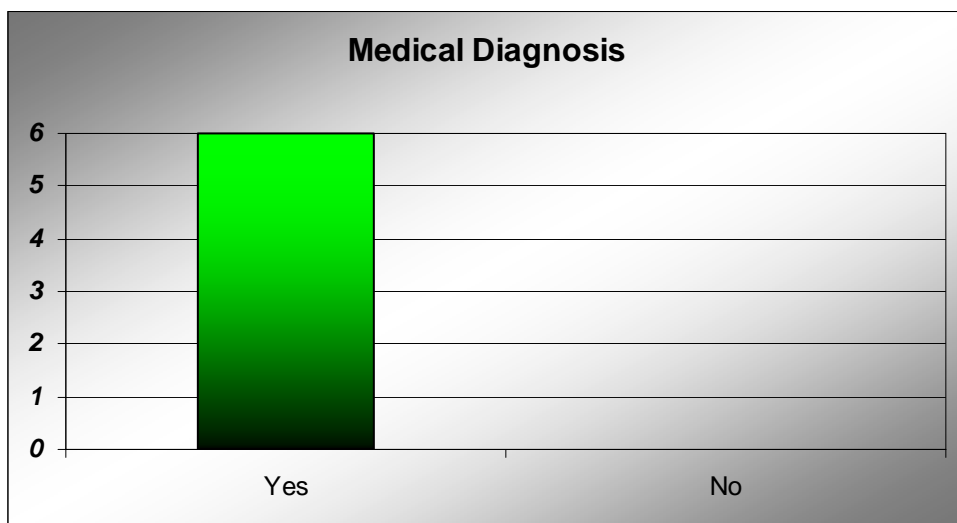


Chart 4. Question #16: Medical Diagnosis

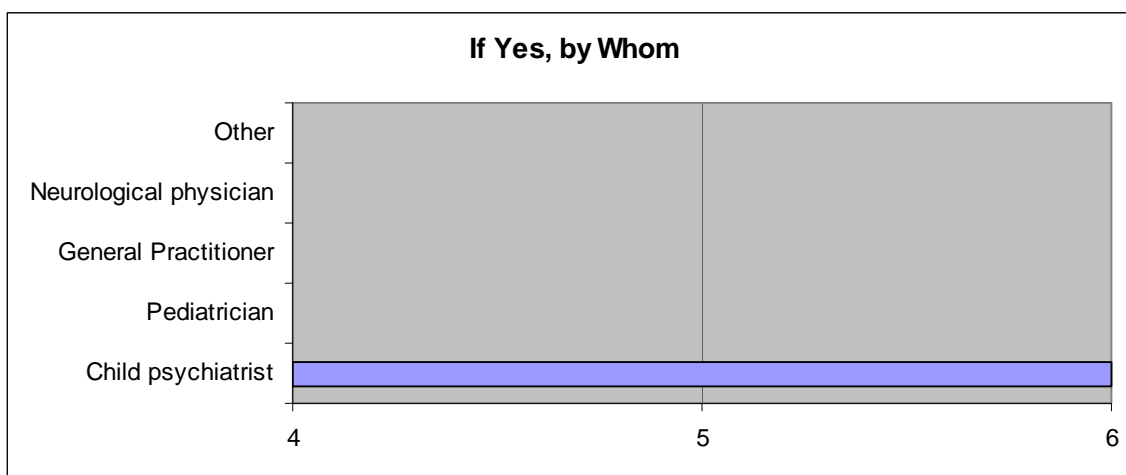


Chart 5. Continuation of Question #16: If Yes, by Whom

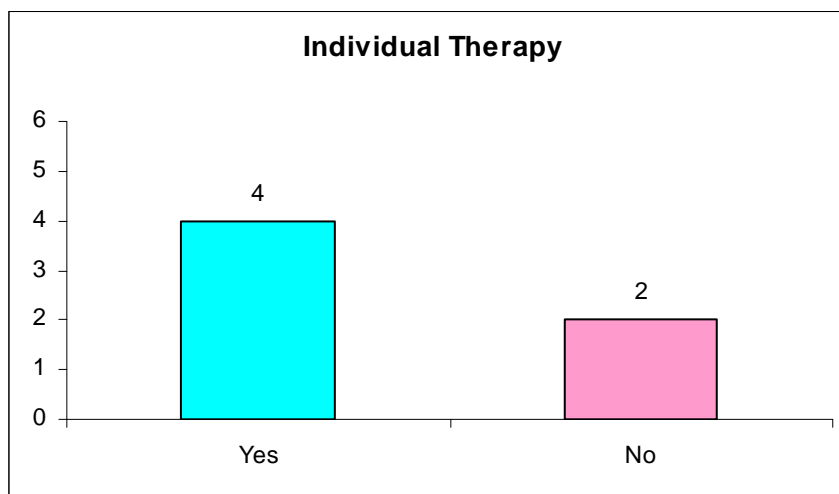


Chart 6: Question #27: Individual Therapy

Beginning ages of individual therapy: 6, 7, 8 and 12

Of the four adolescents who had participated in individual therapy one started at the age of six (parent considered individual therapy helpful and child participated over an extended length of time), one started at the ages of seven for a time and then again at nine (parent considered individual therapy unhelpful), one at the age of eight and continued over an extended length of time (helpful), and one at the age of twelve and continued over a length of time until starting college (unhelpful). This particular adolescent subject participant received no other supports throughout his elementary, middle school and high school experience in contrast to the three others who did and still do. One other parent also considered individual therapy had not been helpful. In this case the adolescent had experienced several changes regarding his diagnosis before eventually being diagnosed with AS at the age of 17.

Consideration could be made that incorrect diagnoses may have contributed to treatment plans that did not meet the needs of the adolescent and therefore the individual therapy fell short of parent expectations.

All six adolescents participated in group therapy (see Charts 7 and 8). Of the last two adolescents mentioned above the adolescent diagnosed at the age of 17 had only participated in group therapy for approximately three weeks before the interview. The parent however considered group therapy as helpful thus far. One parent considered group therapy as very successful for her child. He started at the age of 7 and continued on a regular basis until the age of 15 at which time he began to consider new group members, who were about his age or older, to be immature. However, since leaving the group he continued to cultivate a friendship, via telephone conversations, with one of the group members who joined the group when he did. He and his contact had only just begun to use the telephone as a means of social connection.

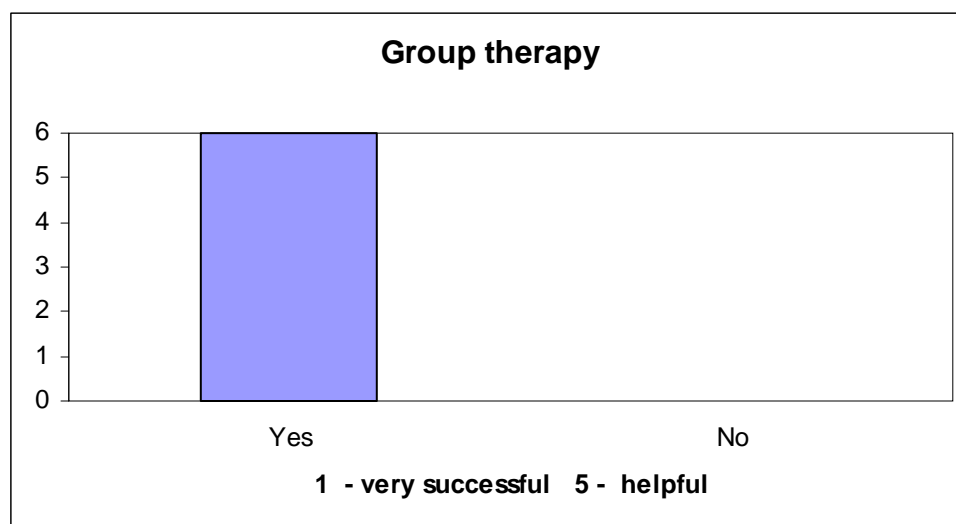


Chart 7. Question #28: Group Therapy

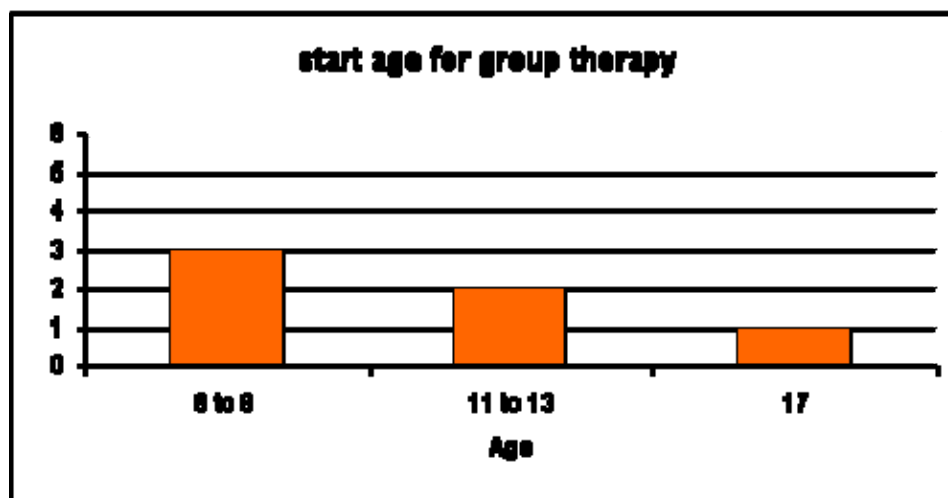


Chart 8: Start Age for Group Therapy

Behavioral and inter-relational interventions. Parent/caregivers were asked to answer several questions regarding their knowledge of interventions specifically for children with autism. One of the most researched interventions is the *Lovaas Applied Behavioral Analysis (ABA)* method targeted towards younger children where one of the goals is to elicit a correct response from a non-speaking child or a child with echolalia. Fifty percent of the parent/ caregivers had not heard of this method and the other 50% who had heard of it did not use it. One parent looked into ABA when her child was one year and three months old but did not implement it as she considered it did not address the real issues her child was experiencing which were sleepless nights. She also shared her son was already communicating verbally between the ages of six and eight months of age.

Greenspan's Floor Time (see Chart 9) also targets the earlier years of children with autism. In Floor Time the therapist follows the child's initiative in the hope that joining in with the child's play will encourage the child to eventually reciprocate actions

by the therapist. Two of the parents had never heard of this method and those that had heard of it did not implement it.

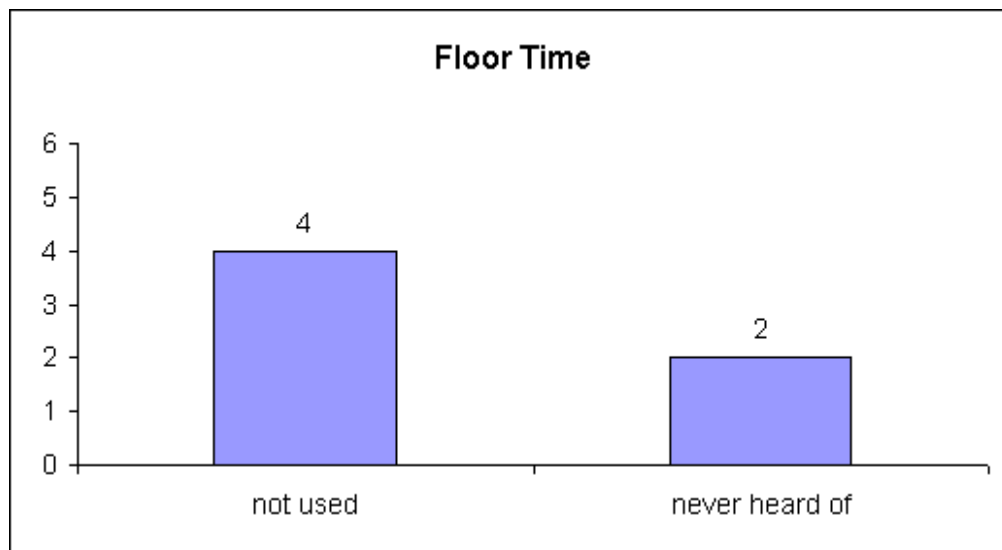


Chart 9: Question #25: Floor Time

Two programs mentioned which are set-up to span the life of a person with autism, were **Treatment and Education of Autistic and relation Communication handicapped Children (TEACCH)** and **Relationship Development Intervention (RDI)**.

TEACCH was recognized by 50% of the parents but never used. Fifty percent had never heard of the method.

Three of the parent/caregivers had never heard of RDI. Three had heard of the method, two had heard of it but never tried it, and the remaining parent answered RDI was tried briefly. Further investigation revealed there was no follow-through sort by the parent or contact made with a certified RDI specialist. Only techniques similar to RDI intervention methods were used to enhance the therapeutic process during group therapy.

As mentioned above all adolescents participating in this study attend or have attended public school. One of the earliest interventions used in public schools for children with autism is the Picture Exchange Communication System (PECS). This is a picture form of communication used mainly for non-verbal children or children who have a difficult time transitioning from one activity to another. Two of the parents had never heard of this method. None of the adolescents in this study used PECS. This is probably due to the verbal ability of the adolescents at the time when such an intervention would have been used in addition to later diagnoses (age nine and seventeen) of all adolescents participants.

Two of the adolescents started speech language therapy; one beginning at age three and one beginning at eight. Both of these adolescents continue to receive this service. One parent consideration of this service was “helpful”, and the other “very successful”. None of the other adolescents received speech language therapy.

Other services available in the public school mentioned in the questionnaire for children with autism were Occupational Therapy (OT) and Physical Therapy (PT) (see Chart 10).

OT is used to address the sensory issues many children with autism have with regards to their sensory systems. These sensory systems include tactile, vestibular, proprioception – knowledge of where muscles and joints are in space, visual, auditory, gustatory and olfactory. According to the questionnaire, five adolescents received OT with varying reports of success from “not helpful” to “very successful”. One of the adolescents began her OT therapy at the age of 11 and was withdrawn from services at

the age of 15. Her parent considered OT “not helpful”. In general, OT services start at a much younger age. The adolescent whose parent considered OT to be “very successful” started OT services at the age of three. She also noted that at her child’s school OT was about the only service available at the time. Another adolescent began his services at the age of nine and another at eleven. The targeted area was assistive technology. Laptops were used by the adolescents to produce written work as both have difficulty in physically writing something down on paper legibly and within an accepted time frame. One adolescent was also provided with a technology called “Naturally Speaking Dragon.” He spoke into an apparatus which then translates his spoken word into typed text. His mother considered this a great help for him.

Only one adolescent participant had received PT between the ages of nine and eleven. According to the child’s parent, this was “not helpful”. He also received OT and SLP services which the parent considered “helpful”. No comment was made regarding the nature of the PT service.

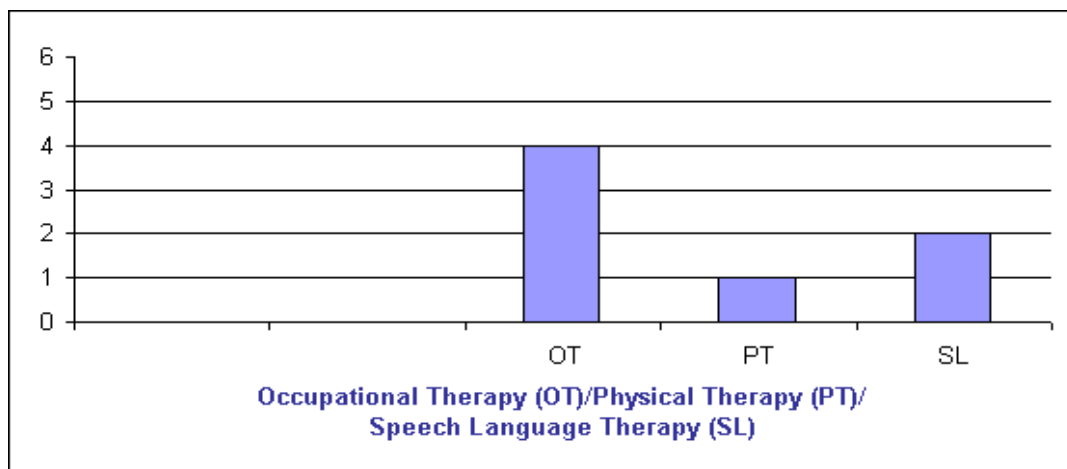


Chart 10. Occupational Therapy (OT)/Physical Therapy (PT)/Speech Language Therapy (SL)

Six adolescents were helped to manage social situations through the process of Social Stories a method devised by Carol Gray (1994). This method is usually presented by a social worker or speech therapist. Social situations are written up in story form as a dialogue the child/adolescent can use to handle a particular interaction. This method was found helpful by all parents. One of the adolescents in high school continues to utilize social stories to help him manage organization. Although this method is a good introduction to managing simple social situations, as mentioned earlier, social causality becomes more complex with age and the stilted presentation of dialogue plus the uncertainty whether the other actor will respond as expected does not meld well with the vicissitudes of life as a person continues his or her development through life's journey.

All of the adolescents except for one, are under the care of a psychiatrist and each diagnosis except one was through a psychiatrist. Two were diagnosed at age eight, four at age nine, and one at age seventeen – this diagnosis was given by a clinical psychologist and later verified by the adolescent's psychiatrist.

Six of the seven adolescent research participants are on medication. Four are on medication for ADHD – *Concerta*, *Adderall*, and *Strattera*. One takes *Celexa* for OCD and *Klonazepan* for anxiety. Three are on *Prozac* for depression. Two take mood stabilizers -- *Trileptal* and *Abilify*. One takes *Trazodone* to help sleep.

In summary: It is interesting that although the parent/caregivers noted they considered educating themselves regarding autism as an important part of their continuing experience almost across the board 50% of the parent/caregivers did not know some of the most well-known therapies available for young persons with autism. It

would not be surprising that some if not all had not *used* them – ABA is expensive and time consuming as well as being geared more towards those with Autistic Disorder. RDI can also be costly and time consuming but does have its roots in encouraging the growth of social interactions and positive relationships. I think it should be considered that the parent/caregivers were originally seeking a reason or diagnosis for their child’s behaviors and not so much interventions during the span of years up to and just after receiving a diagnosis. The answers given may be more representative of their current thinking.

The interventions mentioned like ABA and Floor Time have been around since the late 80’s and late 90’s. The seven adolescents participating in this study were born between 1989 and 1994. All but one was diagnosed around the age of nine. One parent noted that for her first child born in 1991 there were no local or convenient interventions or supports. However, for her second son with autism diagnosed at an earlier age than his brother, there has been so much help and interventions she considers her second son to be doing much better than her eldest son even though her younger son has more severe autism. She continues to worry about her eldest child.

Emotional toll. The onset of their child’s difficulties was still fresh for the parent/caregivers, and not from the date of the diagnosis of HFA/AS but from when their children were toddlers. Each parent recalled the feelings of inadequacy, sometimes shame, and moments of helplessness in trying to manage their child’s needs and behaviors as well as the reactions of others both towards their child and to them as parents. All parents found it painful to watch their children struggle with interpersonal relationships and the stress they believe their children experience due to lack of

interpersonal skills and understanding of social situations. The worry also included how others react to their children. Five of the parents expressed worries about the future and the ability of their children to make it in the world and all parents shared the fear their children may be taken advantage of because of their naïveté. In addition to the emotional drain there was the worry of financial supports and concerns about insurance after their children reach the age of independence. All parents were considering the future of their child but none had made definite plans at the time of the study. One parent expressed concern with local agencies and the care available for young adults with HFA/AS.

From a single case study that entailed a twenty-five year follow-up on a high-functioning child with autism completed by Bolman (2005), it was determined that ongoing services and supports are crucial for a person with HFA/AS in order for them to experience a minimum of a productive life in society. Even with such supports it is recognized that the affect issues for those with autism persist through the developmental years and beyond making the transition to independence a varied and difficult experience.

All the parents were in a good place regarding their children's current behaviors having surpassed the difficult years of elementary school for one adolescent, and middle school for the others. However, all parents gave the impression they knew this was just a respite period and although two parents seemed confident in their adolescent's ability to manage a future for themselves, with supports, the other five parents were not so sure about the prognosis.

Referring to research mentioned earlier by Billstedt, Gillberg and Gillberg (2005), 38% of subjects in their longitudinal study of 120 individuals with autism had a

remarkable problem-free adolescent period. However, a problem-free adolescent period was not necessarily an indicator of continued progress. Sigman and Capps (1997) and Wing (1996) concur that the very nature of autism with its lack of constancy and invariance within the realm of traditional aspects of human development, and the erratic 'learning curve' of children and adolescents with autism make for a slow and plateau effect learning. This often leads to the diminished hope of parents and possibly those who help or are in contact with the child/adolescent with autism. But just as hope fails the child or adolescent demonstrates a skill without any noticed preliminary practice, and hope is restored. According to Wing (1999), these improvements often have no explanation but I posit that at some point in the child/adolescent's life they have experienced the phenomena he or she is now practicing. Because of this it is essential to continue support since, as mentioned earlier, life becomes more complex not less so and new learning and experiencing does not stop. What is apparent for those with HFA/AS is that learning and experience is by no means visceral. Bolman (2005) notes clinical work does not or should not stop with high school completion due to the continuing neurological based developmental differences between persons with HFA/AS and their neurotypical peers.

Adolescents' View and Understanding of HFA/AS

Of the seven adolescent participants six were male and one was female. One interview took place at an adolescent's home. The other six took place in my office. All of the adolescents were comfortable in the setting chosen for their interview and with the interview process in and of itself.

To begin the interview with the adolescent participants, I asked them to tell me what they knew about HFA/AS. Themes emergent when discussing the diagnosis with the adolescents: *indifference, distancing from diagnosis through use of third person, plural and singular, and perceived positives and negatives of having HFA/AS.*

Analysis of the Adolescents' Comments on the Diagnosis of HFA/AS

Compared to their mothers the adolescents' comments on HFA/AS were minimal. All participants emulated an air of *indifference* regarding the question. In addition, all adolescents *spoke in the third person* – plural and singular referring only to parents comments or “they” references regarding the diagnosis of HFA/AS. This presentation gave the impression that the adolescents were distancing themselves from the diagnosis of HFA/AS despite the fact that four out of the seven adolescents shared thoughts of the *positives and negatives of HFA/AS.*

Indifference: All of the adolescents demonstrated a modicum of indifference regarding the diagnosis of HFA/AS. None of them presented as being anxious about the subject of the question or about being diagnosed with HFA/AS. One adolescent replied, when asked what she knew about AS, “I completely forgot”, and went on to say, “All I remember about that information that really pops into my head is that the time when

mother had a book on that subject and she was just asking me questions and I would answer her.” She also said she does not think of AS anymore. Another adolescent said he did not know much “[He’d] ... never read one of the little books on it.”

Third person: With the exception of one, all other adolescents shared some knowledge of the HFA/AS diagnosis in third person plural or singular with statements such as: “I don’t think, because my mother mostly does all the work for it, my mother and father. I don’t really treat myself. I don’t take the pills. They find the pills for me to take them, so.” Another stated, “I have been told that people with my condition, they function very poorly in social situations. They don’t pick up on social cues or norms ...” Others spoke about the traits of HFA/AS without putting themselves into the picture: “...understands it is different ways people think,” “...main thing is difficulty with social interactions.”

Positives and negatives of HFA/AS: Of the five adolescents who recognized HFA/AS all of them had something to say about what they considered the positive or negative side of HFA/AS. Three of the adolescents carried the belief that persons with autism were more adept when it comes to working, concentrating and doing research or academic activities. All recognized the social ineptitudes of those with HFA/AS but also a comment was made that having HFA/AS allows for some insight into others. My understanding of this remark was that those of higher intelligence over time gain this insight due to higher cognitive abilities. Klin (1996) noted that individuals with HFA/AS become despondent, negativistic, or even clinically depressed as a result of their gaining more insight into themselves and others. The understanding of the person with HFA/AS

adeptness for academic achievement may not or does not counter their increasing awareness of personal inadequacy in social relationships.

One of the adolescents stated that he realized people like the researcher want to find a cure for HFA/AS but he preferred if they did not. He thought he had more fun than others because he was never bored like teenagers at his school. Another interviewee who was considering becoming a school psychologist thought he would be able to help others who have difficulties in school because he has HFA/AS. Also, the recent diagnosis of HFA/AS helped one adolescent gain a better understanding of his interactions with family and peers. His subsequent understanding of the disorder helped him manage his tantrums and self-injurious behaviors. On the negative side, it was also shared that HFA/AS could be debilitating.

Physical Presentation of the Adolescents

Physically, a person with autism does not look any different from the rest of his or her peers. However, their verbal and non-verbal behaviors can be quite unique and this uniqueness can and does effect their social interactions.

Apart from the DSM-IV-TR (2005) diagnostic criteria for HFA/AS, several experts on autism, starting with Asperger in 1944 considered certain behavioral presentations peculiar to those with HFA/AS (Frith, 1989, 1993; Wing, 1999). The adolescents who participated in the interviews demonstrated behavioral traits similar to , Wing's behavioral categories of: *aloof; active but odd; over-formal and stilted*, as well as the use of non-variant constant tone of voice and/or loud volume rather than the intonation of typical conversational speech (Asperger, 1944; Kanner, 1943).

Themes of the Adolescents' Presentation during the Interview

There were verbal and non-verbal similarities between the young persons who participated in this research which emerged as commonalities of behavioral presentation during the interviews (see Appendix H for full written descriptions noted down from the adolescents' presentation during the interviews).

The room where the interview took place had a two-seater settee and a matching single chair. After the interviewee indicated the most comfortable seat for him or her which was always the two-seater settee, I sat in the single chair. My chair was set at an angle to the settee. The video camera was placed to my left and to the right of the interviewee.

Physical Anomalies of the Adolescent During the Interview

As mentioned earlier the manner in which persons with HFA/AS connect with the social world is very different from their neurotypical peers. Wing (1999) categorized a set of presentations of persons with AS: *aloof, active but odd, and over-formal and stilted*. Despite the individuality of each and every person with autism, or as one parent put it during her interview: "When you meet a person with autism, you've met *one* person with autism." The pattern of physical presentations by the adolescents during the interview fell into two main categories: *cooperative with disconnectedness*, and *cooperative with connectedness*. From these two categories traits emerged comparable to Wing's (1999) behavioral anomalies mentioned above. The behavior anomalies demonstrated during the interviews were: *active but odd, and formal and stilted*. In addition voice presentation of the adolescents followed unusual speech patterns and

intonation as per Asperger's comments on voice presentation. The noticeable similarities in the adolescents' physical presentation during the videotaped interview did tie one to the other and each to their diagnosis of HFA/AS (Chart 11, p.71).

All the adolescents were cooperative and willing participants in the interview process. Three of the adolescents, who were students of high academic achievement, presented as within the range of "formal and stilted". Two of the adolescents were both formal and stilted. It was difficult for them to stay connected to the interview process. They averted their gaze for much of the interview and showed physical discomfort by hand wringing or pulling of garments and/or changing body position. Also, during times of silence or any technical difficulties with the recording apparatus they showed disconnectedness by looking away from what was happening and showing no inquisitiveness. If the conversation lagged they did not demonstrate any ability with conversational fillers. There was just silence. They managed the answering of questions better than the listening process as they seemed to struggle with staying connected to the interviewer. The disconnection manifested itself through long pauses and short concrete answers. The third adolescent in this group of three demonstrated formal behavior. He was polite and somewhat theatrical in his conversational presentation. He maintained good eye contact and kept the flow of conversation going with appropriate fillers. He was interested in the interviewer and asked questions about the research process. His presentation of politeness and interest seemed to emerge from a veil of formality giving the impression it was a structurally learned behavior – which I hasten to say did not make it any less sincere. Interestingly enough further review into this interviewee revealed he

had never received any supports or interventions during his elementary, middle school and high school years although he had engaged in some individual therapy. During the interview he kept his laptop computer on his knee. It seemed to act as a barrier between himself and the interviewer and may have made for a less anxious experience for him. He never used it although he had said he needed it to take notes.

The only female interviewed, and a student who struggles academically, was more stilted than formal. She was very matter-of-fact when she replied to the questions and, like her two formal and disconnected peers, showed little to no interest in the interviewer. Showing no overt demonstration or sign of anxiety, she gave off an air of aloofness and her answers to the questions were curt and to the point.

The other three male adolescents who manage average to above average in their academic endeavors were actively engaged in the interview process and presented with a sweet nature meaning they smiled and their voices were tinged with happiness and a flavoring of interest in the subjects discussed. Two had a lot of immediate nervous energy one giving quick laughs, and both using rapid speech. The third of this group, who was equally enthusiastic about the interview process, presented with a slower speech pattern and no show of overt anxiety. His interview was conducted at his home and he did have his dog to pet during the interview.

All interviewees demonstrated peculiarities in their speech. Four of the interviewees' demonstrated the typical difficulty of voice volume control experienced by a great majority of people with autism (Kanner, 1943; Wing, 1996). Two kept their voices low, and two raised their volume during the interview. The increase in volume

does not necessarily, and in these cases did not, coincided with any particularly poignant section within the conversation. Three out of the four adolescents had no intonation and their speech was monotonous in presentation.

The three remaining participants, although managing intonation and volume to an acceptable level, all demonstrated a certain pressure or theatrical presentation to their speech. These three participants managed a continuous flow of information compared to the others who preferred to manage the conversation with as few words as possible, and for one whose monotonous tone belabored his sharing of information.

Of extreme interest was the way in which each adolescent participant in this research incorporated the use of their hands to enhance the meaning of their verbal explanations. In all cases these gestures were pertinent to the conversational content shared by the adolescent. This is of interest because Wing (1999) mentions the difficulties of persons with autism have regarding the use and understanding of non-verbal communication. Also, assessment tools like the *Autism Diagnostic Observation Schedule* (ADOS) (Lord et al., 2001), and the *Autism Diagnostic Interview-R* (ADI) (Lord et al., 1994) incorporate into their observations the measurement of ability or lack of use of social gestures. Non-verbal skills are an important predictor of outcome in communicative and social competence and the ability of the adolescents in this study to use appropriate and sometimes skillful gestures is a heartening one.

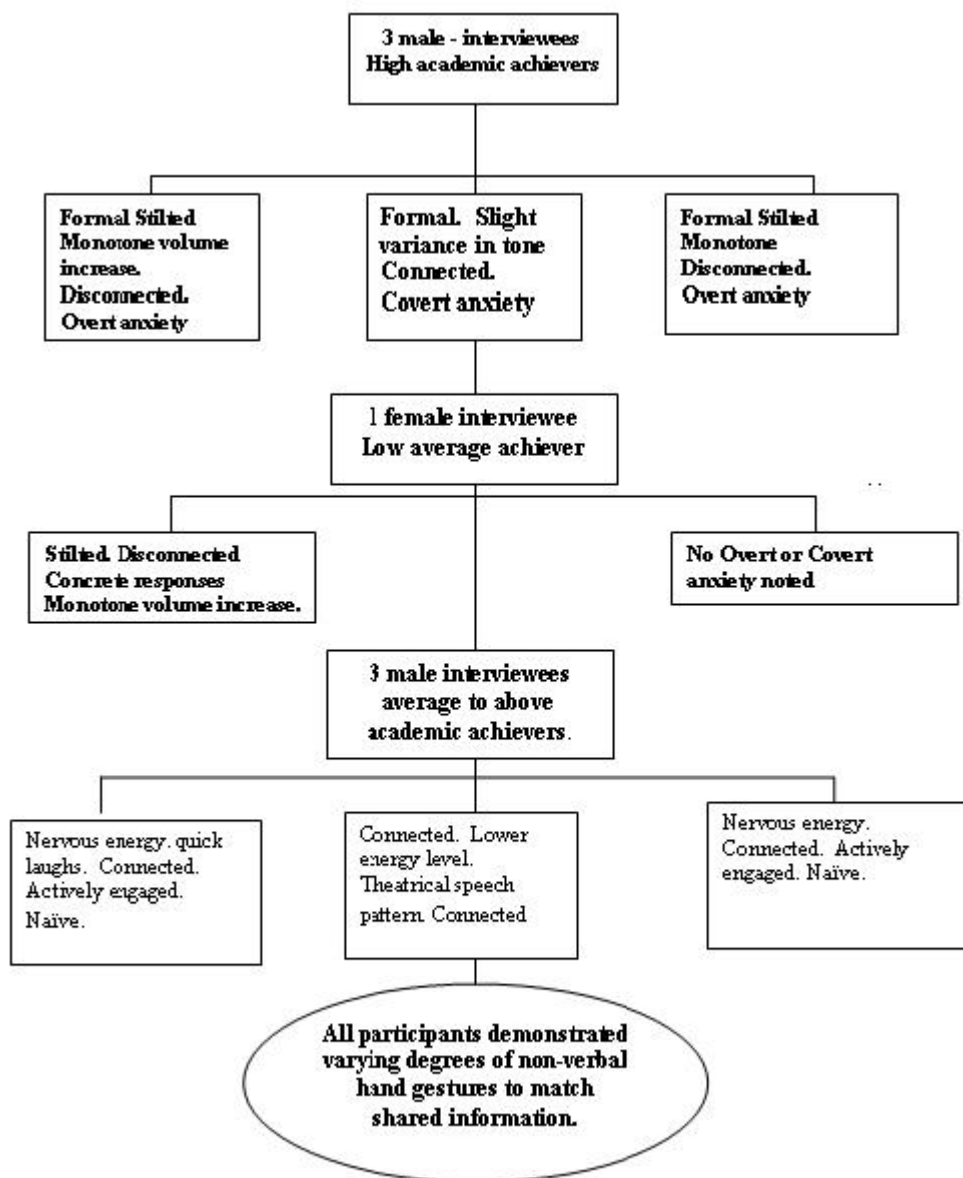


Chart 10. Physical Anomalies of Seven Adolescent Interviewees: 6 Male and 1 Female

Overview

The above emergent themes and patterns regarding the experiences of the parents caring for an adolescent with HFA/AS along with the adolescents' shared thoughts on the diagnosis illuminate the overt worry of the caregivers juxtaposed to the seemingly indifferent response to the diagnosis by their adolescents. One parent stated that she felt she worried about things much more than her son seemed to, and the other parents intimated their worries. However, the physical show of anxiety, albeit subtle, during the interview by all of the adolescents whether they shared more or less about their experiences highlights an undercurrent of concerns and the heavy burden the adolescents carry as they try to make social connections with others and move forward adaptively in the social world.

The following section is the presentation of themes which cross both the parent interview and the adolescent interview regarding social interactions: **restricted social circle; object oriented connections rather than emotional ties; isolation, both self-sort and imposed; and outsider;** will inform on the focal point of this research – the social experiences of adolescents with HFA/AS and the views of their mothers.

Social Experiences of Adolescents with HFA/AS and the Views of their Mothers

From the individual interviews with each parent and each of their adolescents with HFA/AS, a commonality of social and adaptive experiences emerged regarding each adolescent and the view of those experiences by his or her respective parent.

The stressors of earlier years and the management of the then younger children's school experiences and eventual diagnosis of HFA/AS dovetailed into a calmer time as

each adolescent ended their middle school education and entered high school. This calmness introduced a time of conditional respite for the parents from the rigors of managing the ramifications of an Autistic Spectrum Disorder diagnosis, and the management of their children's emotional and school lives. For the adolescents themselves there was a general consideration of transitioning from a place where they did not fit in at all i.e. middle school to a place where not fitting in seemed less crucial.

From the interviews with the adolescent and his or her caregiver the following themes and patterns regarding the social experience and adaptive behaviors across family and community boundaries emerged: *social experience* - **restricted social circle; object-oriented connections rather than emotional ties; isolation, both self-sort and imposed; and outsider.** *Adaptive behaviors* - **lack of independence; lack of vicarious learning; developmental delays; and adolescent's overall reliance on mother.**

Social Experiences

When beginning the discussion regarding the social experiences of the adolescents with HFA/AS in this study there was a definite shift in composure for both the adolescents themselves and for their parent caregivers. To varying degrees the adolescents showed engagement in the subject and also had more to share. The parents lost their pressured speech and made the natural and appropriated switch from recollections of past indignities to present concerns about their adolescents' social experiences and abilities to manage themselves. From different points of view both parents and adolescents described the same set of circumstances regarding social experiences.

Every adolescent in the subject set have *restricted social circles*, and the parent tended to be or had been the social organizer. The adolescents' acquaintances and sometimes 'friends' all moved within the circles of their special education class, an autism adolescent group and/or a church youth group or school club. The family was the only constant social experience, but all parents shared that their children preferred alone time rather than family interactions. The adolescents had been within these restricted social circles for some years. It was only within the past year that two of the adolescents, who met at a group for young people with AS seven years ago, began to contact each other over the phone. These two adolescents are both seventeen years of age and neither had used the phone prior to this for social connection. All adolescents but one used the internet to connect to others to play online games or to chat about anime – a video series from Japan. Parents of two of the adolescents spoke about friendships their sons had, one for several years and the other more recent. Although both parents were happy their sons had a friend, one parent shared that her son and his friend struggled with their friendship and just remained friends to have each other's company. She explained both adolescents had social difficulties although only her son had HFA/AS. The adolescent of this parent did not mention his long time friend during the interview. The other adolescent, who seems to have met his friend a couple of years ago, spoke very highly of his friend and credited him for introducing the interviewee to the church youth group and Christianity. The parent of this adolescent said her son's friend practically lives at their house.

This was not the case for the other adolescents. Both parents and adolescents spoke of difficulties in getting would-be friends to visit. A couple of the adolescents

seemed slightly perturbed by this, one wondering why friends did not come when invited, and one wishing the friends would visit. However, in general it was accepted as just one of those things. The way in which the adolescents considered their would-be friends may underlie the reason no visits materialize. The adolescent subjects have **object-oriented connections** to possible friends rather than **emotional ties**. This means friends are not seen as someone to talk to about feelings or to manage reciprocal contact, but someone only to play video games with or to use as a bench mark for the abilities of the adolescent with HFA/AS. These abilities are usually academic ones. Even the adolescent who so enthusiastically spoke of his friend introducing him to church, only spoke of contact with this friend through video games and anime movies.

Theatrical groups and scholastic teams were a social opportunity for another three of the adolescents. However, difficulties and anxiety at managing contact with more than two people at a time prevented these adolescents from taking advantage of meeting with group members in a less formal context. One adolescent who participates in a theatrical group at high school put it like this:

“With more than one person, it becomes a challenge because then I have to multitask, ‘Okay, what do you think of this? What do *you* think of this? How would you react? How would *you* react? What could I say to you that would interest you as well,’ and vice versa. There are so many things that go into talking with a person that just a neurotypical doesn’t think of, you know? It is a balancing act. With someone with Asperger’s, it’s like you don’t have that, so it’s a struggle once ... you have added ... you have given them one weight [person with Asperger’s] and they can carry that fine, but once you add two weights, now they’re having to balance this and you just keep adding more with more people and it becomes harder to balance.”

This adolescent went on to say that connecting with people through theatre was much easier.

“Well, yeah, I’ve been doing it for a long time. [Started at age five performing in the *Christmas Carol*] Actually, it is kind of strange. I find it easier to perform on stage for people than I do to like perform if I’m not on stage. Like in front of a class I can’t give a speech or anything, but if I’m on the stage, it’s easier. It’s like, it’s like okay.”

He went on to say:

“... when you’re acting and you’ve had quite a while and you know your script and even if you don’t have all the cues right, you can play off the other people. Like, you know, they say something and you think about what they just said, you can kind of remember your lines because you know it has to do with what they just said. It’s like a way of showing some sort of interaction with it being safe because it’s already set, so I’m learning about social interactions. ... it’s like learning about social interactions without randomness.”

The parents viewed their children’s social contacts as shallow. I would surmise that because the parents are so aware of their adolescents’ lack of ability to connect socially with their respective families the parents can only consider the difficulty their adolescent has with managing anything deeper with friends. Also one parent said her son was very annoying and thought this would be an alienating factor in any relationship.

One of the more chatty adolescents said he viewed social interaction as an obsessive trial and error where the trial was he tries to approach to make friends and learns it does not work and the obsession is that no matter how many times he fails he keeps going. He used the metaphor of Thomas Edison trying to come up with a working light bulb, only the adolescent added *he* has just found a couple of thousand ways how *not* to make a light bulb [not a friend]. However restricted and shallow the social circles or contacts may be, the parents are relieved there are some.

The worry the parents carried was that of their adolescent's **isolation** from the social world. This isolation seemed to be both **self-sort** by the adolescents as well as **imposed** by others. The adolescent subjects seemed to have a propensity to want to be alone. Parents spoke about their adolescents retreating to their rooms to play video games or just to read. This in and of itself can be considered typical teenager behavior. However, it is another layer of 'aloneness' for the adolescent with HFA/AS because typical teenagers seek out other teenagers to interact and connect with away from the family hub. This is not the case with the adolescents discussed here.

The seeking of time apart was seen by a couple of parents as a stress reducing process for their adolescents, and a necessity from the daily pressure of having to be in a social setting and trying to manage this. One parent mentioned her child will now periodically visit the family from his basement room, and this made her feel better although she would like more of his time. This particular adolescent mentioned this too and said he loved his family but he *loved* playing his video games. This was a preference for him over family vacations and outings. He would rather be alone playing a video game than participating in family get-togethers. Within this context of seeking isolation, another adolescent's parent shared he withdraws from overtures from young ladies who seemed to like him; much to the mother's disappointment. This may not be a seeking of isolation, but more of not understanding the subtleties of flirtation. All adolescents in this study indicated that they wanted to be included in social interactions but they did not have the skills to manage this.

Considering all adolescents in this study had participated in group and/or individual therapy and all but one of the adolescents had received Individual Educational Plan (IEP) support the questions here would be how these supports or did these supports target skills for promoting ability to socially interact? A request was made to the parents to include a copy of each adolescent's IEP if possible. Only two parents responded.

The manner in which social/emotional goals are managed through the public school system, and this was the case for the two IEPs shared, is via a set of goals and objectives with benchmarks to measure the progress of the student. As mentioned earlier the State of Illinois has specific and standard social/emotional goals and benchmarks to be used to address social/emotional growth within the context of school and life in general. From my own experience as a school social worker and from the goals written in the IEPs acquired from this study, students with HFA/AS are expected to gain skills through managing reciprocal communication and building up abilities to recognize others' verbal and non-verbal reactions.

Only one adolescent in the study mentioned how he noticed groups of peers did not want him around and made a point of ignoring him when he tried to join them. Parents however, mentioned how they saw their children ostracized and left out and how this was a very hurtful experience for the parent. One parent thought she probably was affected more by this scenario than her son.

The general aura of disconnection during the interviews emulating from the adolescents made it difficult for me to ascertain what might be considered the true feelings of the adolescents regarding social connection. All of the adolescents seemed to

want to have social connectedness, but none demonstrated overt anxiety or unhappiness regarding the fact that none had such a connection. The process of socialization for them seemed fraught with complications including inability to get friends to visit with them, and difficulties with expressive language. They were also late starters in managing even the simplest of friendship rituals such as phone calls. Apart from the fact that parents said their adolescents needed or wanted to be alone, and the adolescents *voiced* the wish to have alone time, none of the adolescents stipulated it should be the majority of time.

Parents shared some ideas why their adolescents were isolated. They considered their adolescents annoyed others with their obsession regarding one subject and/or their inability to stop talking about it when others had long lost interest. Their adolescents missed social overtures and cues. Also, their children tended to reiterate rules which they noticed other peers had not followed thereby gaining the label of teacher's pet or just generally a "jerk". Even when another adolescent engaged them in a conversation their child sometimes just walked away when their peer was in mid sentence. All these traits led to isolation of the adolescents by others. Parents agreed their adolescents continue to have on-going difficulties making friends and engaging in social experiences.

Within the culture of adolescence, if you do not belong to a group of friends you are an **outsider**. This is not specific to adolescents with HFA/AS; however, within the context of this study, parents considered their adolescents were misunderstood by others more than normal and consequently relegated to complete outsider status. One parent considered her son was treated like a "weird unworldly alien" although she felt her child did not notice this treatment. One of the adolescents said he tried to explain his thoughts

to other peers, but could not find the right words to express himself and inevitably ended up alienating himself from the very person he wanted to make contact with.

Adolescence is a period of metamorphosis. The change between childhood and adulthood encompasses the beginning of a search for a personal identity and independence. This is often a painful and difficult experience for most teenagers. However, adolescents in this subject pool seemed agreeable with whom they were at this time. Some of the adolescents indicated they wanted to be outsiders. Some did not wish to be part of the “inside” groups because they noticed discrepancies in behaviors by these groups with regards to values. Such as being an A student but still cheating on homework or members enjoying participation in theatre club but talking meanly about the teacher behind the teacher’s back.

Parents mentioned their adolescents interacted with children younger than themselves. Sometimes this was a choice by the adolescent and sometimes, as reported by parents, younger persons were the only ones who would interact with them. One adolescent said although he was seventeen, he knew he was more like a 12 year old. He said he was always a bit behind the line. All of the adolescents were behind the line with regards to adaptive behaviors.

Adaptive Behaviors

There was a **lack of independence** and understanding of independence on the part of each adolescent. Although a formal measure was not taken in this research comments by parents and adolescents made it clear the adolescents had adaptive **developmental delays**. None of the adolescents in this subject group wanted to drive. Firstly, many of

the adolescents had anxiety about driving and their capabilities to manage a vehicle; secondly, none of the adolescents had a good sense of direction. For example, after several years of traveling to and from school by bus their parent/caregivers considered none of the adolescents would be able to find their way home if dropped off the bus any other place than their home. The adolescents also verbalized their difficulties with managing direction. Parents began preparing their adolescent for driving in advance. One parent said she started two years ahead of time. The process of preparation for all parents was asking their adolescent to pay attention to their surroundings as they traveled along in the car with their family and also sometimes to ask the adolescent which direction was home. This was verified by an adolescent who said he was now paying more attention to his surrounding. He said that previous to this if he had been dropped off the school bus anywhere but home he would have no clue where he was or how he would get home.

The lack of ability of **vicarious learning** determined that parents continually explained simple tasks such as how to do laundry or in some cases the general management of personal hygiene. One adolescent participant said, “If my parents died tomorrow I would be like a kite that had its string cut.”

For all parents but one the necessity of managing daily tasks was not a priority. The one parent who was insistent her son manage household chores considered this an essential part of life management. In the other cases, the general sentiment was put by a parent who said “... That was never really a big priority of ours when you have so many

things to worry about. I know that people think that she should have all these responsibilities, but it just wasn't the top priority."

All the adolescents were, however, beginning to learn how to do laundry and manage some household chores such as taking out the garbage, cleaning up their own space at home, or caring for family pets. Despite this, the general consideration was that mother managed everything.

There was an **overall reliance on mother** in particular and the **family** as a whole. This reliance was tinged with extreme naïveté on the part of the adolescent in his or her regard of the social world at large. Little consideration of independence was voiced or seemed cared about. None of the adolescents had dreams of independence. One adolescent presented his look into the future rather like a social story:

"I'm not going [to] be leaving the house for a while, but if I ever do leave the house and move out maybe somewhere and live alone, I'm going to, hopefully, if I have a nice enough neighbor, I'm going to make acquaintances with them first. I've actually gotten good at being friends with people, but I'm going to offer to him, 'If you can drive me to places and I'll pay you money and the gas you spend, you know, then would you please be able to drive me to work every morning and home every evening, and that would probably be about it besides any groceries.' Depending on what they say, it would be okay if they don't, but there are always other people I could probably ask and they might be nice enough. Maybe I could get an old friend to call on the phone."

Parents were hopeful about their adolescents' futures, and at this stage, when so much of the emotional stress had abated, this was a good time to be hopeful. However, parents were cognizant of a future with lots more managing to do for their adolescents.

Summary

This chapter discussed the emergent themes and sub themes gleaned from the videotaped interviews of the parent/caregiver and his or her adolescent with HFA/AS. The sharing of information and the visual presence of the parent produced a story and picture of a long and sometimes painful journey. Beginning with the knowledge that their children were not responding to them as other infants and/or toddlers did, to the seeking of answers from professionals during the pre-diagnosis days, and the eventual diagnosis of HFA/AS for their respective children. The present time proved to be a respite from the challenging behaviors experienced during the earlier and middle school years and the struggles acquiring and managing supports and interventions for their children as they progressed through the school system. The parents' presentation through the interview could be seen as a template for the affect of recollections of the past, the relative calm of the present, and apprehensiveness for the future of their children. There was still a residue of discomfort and some displeasure when talking about the difficulties and sharing their concerns during their children's younger days and/or obtaining a final diagnosis. This was apparent in the verbal and physical presentation during the videotaped interview by most parents. The implication may be that the underlying discomfort demonstrated may enhance the feelings of anxiety for the parents as their adolescents struggle with adapting to the current social world. The parents must again seek professional advice to manage upcoming transitions from high school or college or engage with various agencies that might be of assistance to their children. The present calm, though well appreciated, was not viewed as the end of worries, but as a respite.

The parents could not give a substantial reason for their adolescents' relatively smooth transition into high school or college except to say they thought students in high school were somewhat more understanding. Without a more concrete reason(s) for their children's emergence from what was termed by most parents as a horrible middle school experience during which time their adolescents suffered emotionally there is no viable and/or tried intervention to turn to confidently in the event that things might fall apart again. Because of this, parents although planning for the future, have reservations as to how their adolescent will manage their young adulthood and the society at large.

The adolescents on their part did not seem to carry any worries akin to their parents. They too, were cognizant that middle school was challenging and that high school was better. They verbalized and they understood their social difficulties, but because they have a difficult time expressing themselves emotionally this verbalization did not imply the depths to which this understanding may reach. The concern here being that as children their tantrums and odd behaviors got noticed and attended to but as adolescents and young adults they have become calmer in society. Quietness or calmness does not bring attention. These attributes are not beacons for summoning help. However, the lack of independence and ability to navigate both figuratively and physically in the social world needs to be addressed for these young people.

CHAPTER IV

DISCUSSION AND CONCLUSION

The fourteen participants in this study, seven adolescents and their respective mothers, were good enough to share information that opened a window into some of the social and adaptive experiences of being an adolescent with HFA/AS and of being a caregiver for the adolescent. The answering of questions during a video-taped interview led to the unfolding of a shared story touching on and traveling through some of the most difficult of times for the parents to a place of conditional respite for them and, for the adolescents, a transitional period of life.

Autism Spectrum Disorders fall on a continuum with varying points of severity. If we consider symptoms of the disorder to be the most severe to the left of the continuum the adolescents with HFA/AS in this study would be placed on the far right. From the shared stories of parents and adolescents in this study a point of severity is relative to the experience of life radiating from that point and not the placement of it along a continuum.

Themes that emerged from the interviews – particularly those referring to the social experiences of an adolescent with HFA/AS were verified by both parent and adolescent – *restricted social circle, object-oriented connections rather than emotional ties, and isolation* – both self-sort and imposed.

The experience of life at this point in time for the adolescents and parents who took part in this study is relatively good. The transition to high school has been an uneventful one and the difficulties of middle school, although remembered and recalled, mostly by the parents, are history now.

The interactions of the adolescents during the videotaped interview fell into two categories. Adolescents who demonstrated no difficulty in engaging in the interview process and adolescents whose lack of volubility made it difficult to participate in a flow of relational connection during the interview. Despite these differences in presentation by the adolescents and the assumption one might make that the more connected group would have an easier time building social relationships outside of this context than the less voluble group the stories shared revealed almost identical experiences of social isolation and paucity of friendships. This disconnect from social interactions with others was confirmed by the parents of the adolescents.

Hobson (2000) makes it clear what the challenge means regarding the enigma of autism. The path of life proceeds along a route which involves people to people involvement. For whatever the reason, the syndrome of autism arises and whatever the gifts a person with autism has the disorder of the system for a person with autism is “person-in-relation-to-others”, or in this case, adolescent-in-relation-to-other(s).

Hobson (2000) among others (Ozonoff & Griffith, 2000; Rutter et al., 1999) considers that although the complexities of the phenomena that is autism can be couched in the processes of brain functions such as executive function or particular areas or pathway of neurons in the brain, Hobson is skeptical as to whether the solutions or

answers to questions on how to address the experience of persons with autism with other people and “the interplay of emotionally patterned relatedness” will be solely found in these particular areas or pathway of neurons in the brain. In his book “The Cradle of Thought” (2000) he extrapolates that “The innate sociability of infants taps into the intuitive responsiveness of adults to forge a mental as well as physical development” (p.124). Unfortunately, it seems persons with HFA/AS lack this innate sociability and therefore intuitive responses from peers or a peer is more often than not forthcoming. In fact as was mentioned by a parent in this study her son was treated like some weird unworldly alien. The onus of empathic and meaningful communication with a person with HFA/AS falls on the neurotypical or in other words the person(s) working with and/or supporting these young adults. For although it has been stated above a person with HFA/AS does not have an innate sociability he or she has the desire to be social but lacks the skills. An important question that comes out of this particular research is how can and what are the possibilities for those who are not professionals to help persons with autism feel connected to society? There is an agency that provides Big Brother and Big Sisters for children and adolescents who do not have such support due to either coming from a single family or being an only child with no siblings. Would it not be possible to set up such an agency for young adults and adults with HFA/AS? A agency where volunteers, as the young people in Big Brothers and Big Sister, can give support to individuals with HFA/AS by managing phone trees and/or offering social supports. An agency whose volunteers understand the manifestations of autism and the isolation lack of social skills and adaptive behaviors brings to a person with HFA/AS. The simplest of

supports can sometimes be more helpful than the most complicated behavioral plans. A regular phone call or a planned outing might make a difference. In addition, such contact may ensure that a lone adult is getting enough nourishment and managing appropriate care for his or herself correctly. Also, research on the transitioning young adult would give a window into what is available and what supports are being put into place to help for future needs?

All the adolescents in this study share a finite social experience and all demonstrate the same object oriented connection with peers. The social-emotional connection to others was not overt on the part of the adolescents with HFA/AS in this subject group. However, it does not mean it was not there. It may be necessary for those of us who do not have HFA/AS to listen more carefully and think past the verbal communicative patterns of someone with HFA/AS which initially can seem void of emotion. For example, from the analysis of the initial interview theoretical themes emerged of **restricted social circle; object oriented connections rather than emotional ties; isolation, both self-sort and imposed;** and **outsider** that continued to run through the subsequent interviews. All interviewees heard the same question. The following is the part of the first interview. I asked about going out into the community to do things and this was shared:

“Um, oh, when I’m at college, my community is confined to a 4 x 5 mile radius, but that’s probably too much exaggeration, but I don’t go off campus, especially now that I’m older. The community, uh, every Saturday they show a movie in the student union and I go to those. I’ve only went to a couple. I don’t interact with people very well at college. We say hi or if we’re at one place or if there is somebody I want to talk to at lunch, I will go sit by them. In the library I will say, “Hi how’s it going? See you at this next meeting.”

To the question whether he has a particular friend at college or back at home he goes on to say:

“No, I don’t keep a list of my friends, but I don’t spend any more or less time with them than anyone else and there is no one who I necessarily trust more or less like no best friend or confidants or any of that...”

After another question as to whether he had retained any friends from younger times and still knows was answered:

“...that would be a guy named Robert. He was my best friend in 4th and 5th grade. I kind of used him as my intellectual rival. I participated in this annual writing contest my last three years of high school. In my sophomore year, I was a finalist, and in my junior year I won it again in my senior year. My junior year, Bob was a finalist and he won. He really is something of a genius...”

To the question about contact with Bob now – email for example:

“No. When I come home I basically see my friends at church, but I don't really interact. I've never really said 'Hey, do you want to go get a burger?' or 'Do you want to see a movie?' Usually when I was in cross country or the church youth group, we would get together and go see a movie, but in my whole life I've never had a friend who I [pauses to think] ... well, that's not true [pauses again] not since grade school have I had a friend, who I'd say, 'Hey, want to come over and do something? Do you want meet at this place?' There's no best buddy. I have never had one of those.”

I asked if he missed that to which the reply was:

“It's been so long. I just don't care.”

It was shared by this young man's mother when talking about interaction in social situations:

“Well, now he is 19, so he has learned and he is more verbal. He is aware that he is different and has problems. There are still misunderstandings with communications. He takes things the wrong way sometimes, but I think he understands. After a period of time, he'll come back wanting to talk ...with family members. With peers, he does not have any friends

really. He has acquaintances, people that are on a very basic level. They have a role, but there are no friends he does things with. He likes to be around people but not interact. He will go to a gathering, and he'll sit and read a book. So he thinks he is being social but not interacting.”

She goes on to mention that even though he is at college she manages all his finances. She worried he might do or say something to get himself into trouble and in a way would rather have him at home with her always. Interestingly enough, during his interview he mentioned he thought his mother did not want him to be at home forever. He also remarked he had not really left home and still had one foot in the door and concluded if a meteor hit his house and his family died, he would not know what to do. Poetically he said, “I would kind of feel like a kite, like the string is cut.” The other adolescents in the subject pool are not at the point of leaving home as yet, but all demonstrate a level of dependence at higher levels than would be expected of adolescents their age. Parents of these adolescents do not necessarily want them to stay at home for life but they wanted them close by.

The particular young man mentioned above is about three years ahead of the other participants in this study in his experiences. He never received any special educational support during his elementary, middle school or high school days but his social experiences are no more or less than the other adolescent participants in this study. He also seems to be in the same place with regards to dependency on family.

The idea of ‘dependency’ is interestingly addressed by Bowlby (1980, p. 44) in his “An Information Process Approach to Defence.” Bowlby recognizes the ambiguity of the term ‘dependent’ where it can either be used as an emotional quality of an attachment or merely as a reliance on someone else to provide goods and services. He therefore

defines dependence as the extent to which one individual relies on another for his or her existence and, within this capacity, as a functional reference. He goes on to say that dependence is maximal at birth and diminishes more or less steadily until maturity is reached.

I find this interesting because of what Bowlby (1980) goes on to say regarding his theory on defence – after beginning his chapter on this subject with a quote from Goethe, “*We see only what we know.*” He draws attention to the central control of sensory flow from external or internal sources to the person within the context of neurophysiology and cognitive psychology. This sensory processing occurs in a succession of stages at extraordinary speeds; and all but the most complex occurs outside of awareness. Much of the inflow of information is routinely excluded to prevent overload of the system so this selective process is both necessary and adaptive and in certain adverse circumstance during childhood necessarily so. However, circumstances change as one reaches adolescence and adult life and as Bowlby states “the persistent exclusion of the same sort of information may become maladaptive” (p. 45).

In Chapter III it was mentioned that as hope begins to fail for a person or caregiver who is striving to help a child with autism leading that person to consider his or her help as futile; suddenly the child will manage to accomplish or perform a necessary skill without any noticed preliminary practice or explanation (Wing, 1999). The adolescents in this research all experienced difficulties through middle school some so severe two were hospitalized. However, as they all transitioned out of middle school into high school suddenly, without any reported revelation, things seemed to run more

smoothly for both the adolescent and consequently for the caregiver. Parents are not asking why, their adolescents are doing well. I am skeptical that things can happen out of the blue and contend that the adolescents in this study reached a stage where even though their social adaptive behaviors are way below their peers; they now seem to have the ability to manage information that is adaptively pertinent to their education but not necessarily their social life.

There were pointers the adolescents and parents themselves brought up regarding the beneficial experience of high school. The adolescents shared they considered peers were more forgiving and/or accepting at high school. There were also academic and creative extracurricular activities available for the adolescents to join. The transition for the particular adolescents in this study from middle school to high school was like stepping from night into day. Even though the sample in this study is small the information gleaned from the subjects supports further research into the social experiences of pre-teen and teenagers with HFA/AS in middle school. Questions should target what is being done to prepare adolescents with HFA/AS manage the social and adaptive transitions in life. Despite the relatively smooth transition into high school for the adolescents in this study there continues to be deficits in the areas of socializing and adaptive behaviors. One of the most outstanding deficits adaptively within this study was the ability and/or desire to drive. Culturally, here in America the car is not just a means of transportation it is a rite of passage into young adulthood whether affordable and/or available. However, none of the adolescents in this study wanted to drive although nearly all of them were eligible and one had his driver's license. In a country with minimal

public transportation options, especially outside of urban areas, how will persons who cannot, or do not want to drive manage their work and social lives?

The adolescents were nervous about the responsibility and anxious about the process of driving. The parents did not appear so nervous about the prospect and some seemed determined their adolescent would drive eventually. The preparation by some parents started nearly two years in advance before their adolescent was even eligible for a driving permit. In planning the future of a young person with HFA/AS the ability to drive or not should be considered as well as the availability of transportation in proximity to college and/or work.

The mothers in this study were the scaffolding of their adolescents' existence. Their adolescents showed no lean towards choosing same age peers as confidants which is often an expected trait during adolescent development. The fact that the adolescents in this study were relatively happy and school-wise stress free did not make for a good friend base or busy social calendar.

Concluding Notes

The adolescents in this study had a limited repertoire of social and adaptive skills and social experiences other than those determined by family or school based initiatives. Their social circles remain limited where acquaintances are restricted to a therapeutic group for adolescents with HFA/AS, church youth groups or extracurricular activities at school. And all but two had no close friend or group of friends. As it was suggested in the Special Education Elementary Longitudinal Study or SEELS earlier on, young people with autism have very little contact with anyone. The impairments of autism continue to

impede the ongoing progress of sustaining, maintaining and managing social experiences and the art of belonging in the general milieu of society.

Attending middle school, as reported by each parent/caregiver expect one, was a traumatic experience for their children. The adolescent of this parent when asked about the differences between middle school and high school shared this:

“Um, I kind of learned that I feel negative when someone calls me a name. I learned that if I look at it in a positive way, it doesn’t hurt at all. That’s the major difference. ... Somewhere in middle school I learned that ... when someone called me annoying, I said, ‘Yes I am. When did you notice? Something like that. ... I accept it in a positive way.’”

She was the only female in the group. Her parent was more satisfied with the help the family had received along the way than the other parent participants. This parent’s perception of middle school was that it had been a relatively positive experience compared to elementary school. Could this be the reason her daughter managed middle school in a more positive fashion? The conundrum here is that she managed high school no better than her peers in this study who had experienced trauma in middle school, and was only connected loosely to students who were in special education with her and a young man her age she had met attending a group for adolescents with HFA/AS.

Further research concentrating specifically on the transition from elementary grades to middle school grades would be of benefit especially from the three perspectives of parent, child, and teaching/support staff. Unfortunately, transitions within the school special education criteria are only considered at age 14 – somewhat belated for those who have suffered through the middle school experience. The transitioning process for students moving from fourth grade to fifth grade usually consists of a brief visit to the

new school which includes touching bases with their teachers and a lesson in managing school lockers. In my experience anything over and above this depends on the supporting staff engaged in the care of any child with special needs.

The non-linear developmental progression and the complex idiosyncratic behaviors of a person with autism require innovated forms of research such as, for example, Chaos Theory. Guess and Sailor (1993) looked into the science of Chaos Theory and its macro analytic approach to research and the way the theory is set to trace phenomena with its dynamic view between strict determinism and total randomness. The shifts in autistic behaviors which can stagnate for long periods and then swiftly change, as has been partially reported in this study, may be suitable subjects for Chaos Theory based research. Chaos Theory follows a systems based approach to research which allows for information from varying disciplines to be compared and contrasted within the context of particular phenomenon.

Another important aspect of research concerning the ongoing disorder that is HFA/AS is the time beyond young adulthood. The suggestion in the literature that adults with autism can end up alone and separated from society should be continued to be explored as well as a wake-up for all persons involved in the care of persons with autism. The parents in this study have done and continue to do everything they can for the betterment and security of their children's present and future life. There are looking for help now as the realization of them not being around forever seems closer.

Suggestions for Support

A young man in England with AS has been under the care of a social worker since he was about 16. He is now in his late 20s. The young man was supported by different professionals to manage his difficulties which included not being able to take a train to the only place where he would eat, even though the journey would be drastically shortened if he did not insist on taking three buses. Through support and skills training he changed his behaviors and can now get to his favorite restaurant in 30 minutes by train instead of a two hour bus ride. He lives on his own and all he needs is for the social worker, he has known for years, to check in with him regularly by phone or for him to be able to call her if he is unsure about something and also to help manage his Obsessive Compulsive Disorder (OCD). With this support he was able to return to college to pursue a degree in mathematics.

Persons who live in so called 'blue zones' in the world – places where they live long, healthy and happy lives incorporate into their pattern of good eating habits, and exercise a connectedness with others. A group of centenarians in Japan call each other regularly just to make sure everything is okay. No long conversations just a touch stone of contact. Such a phone tree should be set up for persons with autism. They may not say much but they do appreciate contact. My experience working with those who have HFA/AS, has informed me that a person with autism will not call you but waits upon a call from another person. One adolescent in particular that I know waits in hope that someone will call him. They never do.

The ability of social workers to be brokers for persons with special needs is not a new one. However, the scattering of social workers throughout the complex areas of societal needs does not always make them the first go-to person when it comes to facilitating for those with HFA/AS. Specific disciplines such as OT and SLP are very much connected to the service of those with autism but social workers not necessarily so. School Social Workers can and probably do work closely with persons from other disciplines to manage supports for those with HFA/AS, but it would be good policy for those considering to work in the educational field to have specific and certified training for this most complex of diagnoses, particularly as the incidence of autism continues to grow.

Limitations

The homogeneity of the sample population of this research – all subjects were Caucasian from intact families with a yearly income of at least \$91,000 – except for a widow whose income was now reduced to between \$20,000 and \$50,000 impedes the possibility of generalizing the results. In addition, the pool of subjects is from one geographical area. All were born and raised within the same area and some of the adolescent participants had spent time at the clinic where I work. This knowledge made for a more secure feeling for the adolescents participants and their caregivers and this familiarity may have affected the results. However, it is considered that the information in this study is pertinent and helpful in the on-going investigation and continuing search for improved supports and interventions for those with High Functioning Autism and Asperger's Syndrome.

APPENDIX A

SUBJECT RECRUITMENT LETTER (CLINICAL POPULATION)

Date:

Name of Researcher

Subject Name
Address

Return Address

Re: A Research Study You May Be Interested in.

Dear Parent:

I am writing to tell you about a research study I am conducting in order to fulfill the requirement for a Doctor of Philosophy (PhD) at Loyola University Chicago. The research title is "Social Experiences of Adolescents with High Functioning Autism (HFA) and/or Asperger Syndrome (AS) – Their perceptions and the views of their caregivers: An Exploratory Study." I am seeking the participation of fifteen (15) adolescents with High Functioning Autism (HFA) or Asperger Syndrome (AS) and a caregiver for each adolescent making a total of thirty (30) participants.

The purpose of the study is to gain knowledge about the social experiences and management of daily routines of an adolescent with HFA or AS as reported by the adolescent him or her self and of his or her parent/caregiver. The study involves a questionnaire for the parent/caregiver and video taped interview between the researcher and adolescent, and one between the researcher and the parent/caregiver. Time needed for participation is estimated at 30-40 minutes for the questionnaire and 30 minutes each for the interview.

Having worked extensively with children and adolescents with HFA or AS the researcher realizes requests to participate in some experiences can be stressful for such children or adolescents but hopes that timely preparation will alleviate such stress. With this in mind no foreseeable risks involved in participating in this research are expected.

There are no direct benefits to you or to your adolescent for participating in this research study. However, it is hoped that the results will help us understand the social experiences of an adolescent with HFA or AS better and information gathered from this research study will not only add to the pool of research but also help to promote appropriate interventions and services for adolescents with HFA/AS and their families.

I am including a copy of this letter for you to sign and mail back in the enclosed stamped addressed envelope if you are interested in participating in this study. Returning the letter does not mean you have any obligation to join the study; it simply means you would like to receive more information.

Thank you in advance for considering this request.

Sincerely yours:

Patricia Kunz, LCSW

APPENDIX B

SUBJECT RECRUITMENT LETTER (PARENT GROUP)

Date:
Parent Group
Address

Name of Researcher
Return Address

Re: A Research Study You May Be Interested in.

Dear Parent:

I am writing to tell you about a research study I am conducting in order to fulfill the requirement for a Doctor of Philosophy (PhD) at Loyola University Chicago. The research title is "Social Experiences of Adolescents with High Functioning Autism (HFA) and/or Asperger Syndrome (AS) – Their perceptions and the views of their caregivers: An Exploratory Study." I am seeking the participation of fifteen (15) adolescents and a caregiver for each adolescent making a total of thirty (30) participants.

The purpose of the study is to gain knowledge about the social experiences and management of daily routines of an adolescent with HFA or AS as reported by the adolescent him or her self and of his or her parent/caregiver. The study involves a questionnaire for the parent/caregiver and video taped interview between the researcher and adolescent, and one between the researcher and the parent/caregiver. Time needed for participation is estimated at 30-40 minutes for the questionnaire and 30 minutes each for the interview.

Having worked extensively with children and adolescents with HFA or AS the researcher realizes requests to participate in some experiences can be stressful for such children or adolescents but hopes that timely preparation will alleviate such stress. With this in mind no foreseeable risks involved in participating in this research are expected.

There are no direct benefits to you or to your adolescent for participating in this research study. However, it is hoped that the results will help us understand the social experiences of an adolescent with HFA or AS better and information gathered from this research study will not only add to the pool of research but also help to promote appropriate interventions and services for adolescents with HFA/AS and their families.

I am including a copy of this letter for you to sign and mail back in the enclosed stamped addressed envelope if you are interested in participating in this study. Returning the letter does not mean you have any obligation to join the study; it simply means you would like to receive more information.

Thank you in advance for considering this request.

Sincerely yours:

Patricia Kunz, LCSW

APPENDIX C

CONSENT TO PARTICIPATE IN RESEARCH

Letterhead with contact information

Date:

Project Title: Social Experiences of Adolescents with High Functioning Autism and/or Asperger Syndrome: Their perceptions and the views of their caregivers. An Exploratory Study

Researcher: Patricia Kunz, LCSW

Faculty Sponsor: Alan J. Levy, PhD., LCSW

Dear Parent/Guardian:

Thank you for showing interest in the above mentioned research study.

You and your child with High Functioning Autism (HFA) or Asperger Syndrome (AS) are being asked to take part in a research study being conducted by Patricia Kunz for completion of a dissertation as a requirement for the degree of Doctor of Philosophy (PhD.), under the supervision of Alan J. Levy at the School of Social Work, Loyola University Chicago.

You are both being asked to participate because of your experiences as a parent and adolescent living with this diagnosis.

Please read the following carefully and ask any questions you may have before deciding whether to participate in the study.

Purpose:

The purpose of this study is to gain knowledge about the social experiences and management of daily routines of an adolescent with HFA or AS reported by the adolescent him or her self and his or her parent/guardian.

Procedures:

If, as a parent/guardian, you agree to be in the study, you will be asked to:

- Complete a questionnaire which asks for general family information and for information about supports and/or interventions tried specific to your adolescent's diagnosis. This questionnaire takes approximately 30 – 40 minutes to complete.
- The questionnaire will be sent to you and can be completed at home with the option to call or meet with the researcher at anytime to ask any questions or concerns that might arise.
- Participate in a videotaped interview. During the interview you will be asked to give your view of your adolescent's social relationships and interactions as well as inform on how your adolescent manages day to day routines at home and within the community.
- The videotaped interview should take no longer than thirty (30) minutes and can be stopped whenever you want to. We will meet in a safe, private place and at a convenient time decided between you the researcher.

Risks/Benefits:

Having worked extensively with children and adolescents with High Functioning Autism or Asperger Syndrome the researcher realizes requests to participate in some experiences can be stressful for such children and adolescents but hopes that timely preparation will alleviate such stress. With this in mind no foreseeable risks involved in participating in this research beyond those experienced in everyday life are expected.

There are no direct benefits to you or to your adolescent for participating in this research study. However, it is hoped that the results will help us understand the social experiences of an adolescent with HFA or AS better and information gathered from this research study will not only add to the pool of research but also promote best practice interventions and services for adolescents with HFA/AS and their families.

Confidentiality:

Confidentiality is of the utmost importance during any research endeavor and, with the exception of reporting any child/adolescent/elder abuse or neglect as required by law as a Licensed Professional Clinical Social Worker will be adhered to in the strictest manner. Therefore no identifying information will appear on the parent questionnaire. Instead, a number will be substituted regarding personal information. A separate sheet will be attached to the questionnaires asking for participants' names and contact information.

On return of the questionnaires this sheet will be removed and placed in a separate and secure place and only made available to the researcher and supervising professors as will the completed questionnaires. With regards to the storing of videotaped material this will also be stored in a separate and secure location. First name only will be used during the interview and upon request this will be "peeped" out. Additionally, any information mentioned that would lead to identification of any person or establishment will be removed from the videotape. If the videotape is processed by any other than the researcher the participants will be informed and a signed acknowledgment of confidentiality will be required by the person editing the video tapes.

In addition to signing your agreement for you and your adolescent to participate in this study you will be asked to sign a form regarding authorization to use and disclose (Release) health information for this research study. The health information regards your adolescent's diagnosis of autism. No other health information will be required.

At the conclusion of the research all questionnaires and videotapes will be destroyed. Prior to the destruction some video footage, with consent, may be used during the defense of the researcher's dissertation. Although first names may be heard on the videotape there will be no names or identifying information connected to the survey form. In the written dissertation names will be changed for reasons of confidentiality.

Voluntary Participation:

Participation in this study is voluntary. If you or your adolescent does not want to be in this study, you do not have to participate. Even if you decide to participate, you are free not to answer any question or to withdraw from participation at any time without penalty. Any participants who are currently known to the researcher or who are receiving any services from any facility she is connected with or any participants not known to the researcher who are receiving services from the cooperating research institution will experience no change or effect with regards to any services they are currently receiving.

Contacts and Questions:

If you have questions about this research study, please feel free to contact Patricia Kunz at (815) 566-0521 or patricia.kunz@comcast.net or Alan Levy, PhD at (312) 915-7094 alevy@luc.edu If you have questions about your rights as a research participant, you may contact the Compliance Manager in Loyola's Office of Research Services at (773) 508-2689 or JoAnn Glacken, Compliance Manager at UIC College of Medicine, (815) 395-5942.

Thank you for taking the time to read this letter. Please call if you have any questions or concerns (815) 566-0521. Consent to participate is on the following page. If you understand everything that has been mentioned above please sign both copies of consent – keeping one for your records and return one to the researcher in the enclosed stamped address envelope.

Letterhead with contact information

Date:

Project Title: Social Experiences of Adolescents with High Functioning Autism and/or
Asperger Syndrome: Their perceptions and the views of their caregivers.

Statement of Consent:

Your signature below indicates that you have read and understood the information provided above, have had an opportunity to ask questions, and agree to participate in this research study.
You will be given a copy of this form to keep for your records.

Participant's Signature (Parent/Guardian)

Date

Participant's Signature (Adolescent)

Date

Researcher's Signature

Date

I give consent for part of video taped interview of my adolescent to be used for dissertation defense.

Parent/Guardian

Date

I give consent for part of video taped interview to be used for dissertation defense.

Adolescent

Date

I do not give consent for part of video taped interview of my adolescent to be used for dissertation defense.

Parent/Guardian

Date

I do not give consent for part of video taped interview to be used for dissertation defense.

Adolescent

Date

APPENDIX D

RELEASE HEALTH INFORMATION

Authorization To Use And Disclose (Release) Health Information For the Research Study:

“Social Experiences of Adolescents with High Functioning Autism and/or Asperger Syndrome: Their perceptions and the views of their caregivers. An Exploratory Study”

State and Federal laws, including the Health Insurance Portability and Accountability Act (HIPAA), require researchers to protect your health information. This form describes how researchers, with your authorization (permission), may use and release (disclose and share) your adolescent’s protected health information in the above mentioned study. **Please read this form carefully.**

You and your adolescent have been asked to take part in a research study. The study has already been described to you in a separate consent form. By signing this form you are permitting, Patricia Kunz, LCSW, a doctoral student at Loyola University Chicago, and a staff member of The College of Medicine, UIC, Rockford, Illinois to create, get, use, store, and share protected health information that identifies your adolescent for the purpose of this research study.

Description of protected health information that may be used and released (disclosed or shared)

The health information includes all information created and/or collected during the research as described in the ‘Consent for Participation in Research’ entitled: “Social Experiences of Adolescents with High Functioning Autism and/or Asperger Syndrome: Their perceptions and the views of their caregivers. An Exploratory Study” Protected health information may include results from surveys or video taped interviews that are part of the research.

The health information includes clinical and/or school based assessment for Autism without retardation (High Functioning Autism) and/or Asperger Syndrome. No medical records will be accessed by the researcher and the information regarding health information will be as reported by parent/guardian of the adolescent.

Research use of your adolescent’s protected health information:

The researcher (Patricia Kunz, LCSW) and her dissertation committee members agree to protect your health information and will only share this information as described in this Authorization and the research consent form.

Expiration of Authorization

This Authorization expires at the end of the study, but can be canceled sooner if you or your adolescent decided to withdraw your permission.

Withdrawal or removal from the study

You may change your mind. Your adolescent may change his or her mind and cancel this Authorization at any time. To cancel this Authorization, you must write to: Patricia Kunz, LCSW, 5423 Shoshoni Trail, Rockford, Illinois 61107.

If you cancel this Authorization, you or your adolescent may no longer be allowed to take part in the research study. Even if you cancel this Authorization, the researcher may still use and disclose health information she has already obtained to maintain the integrity and reliability of the research and to report any adverse (bad) effects that may have happened to you or your adolescent.

Contact information for questions about my rights under HIPAA

If you have questions or concerns regarding your privacy rights under HIPAA, you should contact the University of Illinois at Chicago Privacy Officer at Ph: (312) 996-2271.

If you have not already received a copy of the Notice of Privacy Practices, you should ask for one. You will be given a copy of this Authorization after it has been signed to keep for your records.

Right to Refuse to Sign this Authorization

You do not have to sign this Authorization. However, because the health information is required for research participation of your adolescent, you and your adolescent will be unable to participate in the research study. Not signing this form will not affect any part of related treatment, payment or enrollment in any health plans or your eligibility for other medical benefits for you or your adolescent.

Printed name of Subject

Signature of Parent/Guardian or
Legally Authorized Representation of
Subject

Date

Printed name of Parent/Guardian or Legally Authorized Representative of Subject

Describe relationship to subject including the legal authority this individual has to act on behalf of the subject. (Check one below)

- Parent
 Medical Power of attorney/representative
 Legal guardian
 Health care surrogate
 Other; specify

Thank you for taking time to review this document.

APPENDIX E

ADOLESCENT ASSENT TO PARTICIPATE IN RESEARCH

Contact information of the Researcher

Date:

Project Title: Social Experiences of Adolescents with High Functioning Autism and/or Asperger Syndrome: Their perceptions and the views of their caregivers.

Researcher: Patricia Kunz, LCSW

Faculty Sponsor: Alan J. Levy, PhD., LCSW

Dear Adolescent:

I am asking you to take part in a research study because I am trying to learn more about how you spend free time or time with any friends and what you like to do when you are not working on school assignments. Also, I would like to know what you think about autism.

If you agree to be in this study I will ask you to tell me about how you spend time, and what you think about autism. We will use a video camera to record what we are saying to each other and it should only take about 30 minutes at the most.

If you think it would be OK to take part in the research some of the risks you may worry about are about feeling nervous or worrying about not knowing what to say. The things that you share with me may be helpful for other adolescents who have autism.

Please talk this over with your parents before you decide whether or not to participate. I will also ask your parents to give their permission as well as asking one of your parents to take part in the research study as well. But even if your parents say "yes" you can still decide not to do this.

If you don't want to be in the study, you don't have to participate. Remember, being in this study is up to you and no one will be upset if you don't want to participate or even if you change your mind later and want to stop.

You can ask any questions that you have about the study you can call me (815) 566-0521. If I don't answer exactly when you call leave me a message and I will call you back as soon as I can.

Signing your name at the bottom means that you agree to be in this study. You and your parents will be given a copy of this form after you have signed it.

Name of Subject

Date

Signature

Age

Grade level

APPENDIX F
PARENT/CAREGIVER QUESTIONNAIRE

CONFIDENTIAL

#_____

Please complete the following by either filling in necessary information or checking appropriate category.

1. Child's Birth date: ___/___/___ Child's Sex: ___ Female ___ Male
2. What is your relationship to the child? ___ Mother ___ Father ___ Grandparent
___ Guardian (Please specify)_____
3. Age range of person completing form: < 29 () 30-40 () 41-50 () 51-60 () 61-70 ()
Age of spouse/partner: 30-40 () 41-50 () 51-60 () 61-70 () > 70 ()
4. Relationship: ___ Married ___ Divorced ___ Re-married
___ Widow/Widower ___ Separated ___ Single ___ Partnered not married
5. Race/Ethnicity:_____
6. Education: Spouse; Partner; Guardian:
Spouse: ___ HS Diploma ___ GED ___ Some College ___ 4 year degree ___ Graduate
Partner ___ HS Diploma ___ GED ___ Some College ___ 4 year degree ___ Graduate
Guardian ___ HS Diploma ___ GED ___ Some College ___ 4 year degree ___ Graduate
7. Primary caregiver?_____
8. Are you currently employed outside the home? ___ Yes ___ No
If YES, how many hours per week? _____
9. What type of job do you currently hold?_____
10. Is your spouse/partner currently employed outside the home? ___ Yes ___ No
If YES, how many hours per week? _____
11. What type of job does your spouse/partner hold? _____
12. What is your total family income (including all sources of income)?
< \$20,000 ___ \$20,000-50,000 ___ \$51,000-70,000 ___ \$71,000-90,000
___ \$91,000 and above
13. Have either you or you spouse/partner given up work in order to care for your child with Autism? ___ Yes ___ No
14. Have you as caregiver(s) considerate future support(s) for your child with Autism?
___ Yes ___ No
15. At what age was your adolescent diagnosed with HFA/AS? _____

16. Was this a medical diagnosis? No Yes
 If Yes by whom? Child psychiatrist Pediatrician General Practitioner
 Neurological physician Other _____
17. Was the diagnosis made through members of a school based educational team?
 No Yes
 If Yes please check and/or add those who participated in the assessment.
 School psychologist School social worker
 Speech Pathologist Occupational therapist
 Physical therapist
 Other _____
18. Does your adolescent with HFA/AS have any siblings? No Yes
 Please provide the following information:
- | | Sex | Age | Sex | Age | Sex | Age |
|-----------------------|-------|-------|-------|-------|-------|-------|
| Biological Sibling(s) | _____ | _____ | _____ | _____ | _____ | _____ |
19. Have any siblings received a diagnosis of HFA/AS?
 No Yes (please explain):

20. Is your adolescent with HFA/AS currently taking any medication?
 No Yes
 If YES please indicate medication(s) and reason for taking medication(s):

21. Are you an active member of a parent/family group for children with HFA/AS?
 No Yes – If YES, approximately how many hours per month do you spend on activities/meetings? _____ hours per month.
22. Is any other family member an active member of a HFA/AS support group?
 No Yes – If YES, please identify the family member (sibling, spouse, grandparent etc.) and the number of hours spent per month in group related activities.
- Family member: _____ # of hour's _____
 _____ # of hour's _____

**Please describe any clinical intervention your adolescent with HFA/AS received in the past.
Interventions such as:**

23. The *Lovaas* or Discrete Trail method or Applied Behavioral Analysis ABA.

NO YES Never heard of this method.

If YES please indicate age of your child during intervention: _____

Was the intervention maintained over a long period of time and/or to completion?

YES NO. If NO please explain circumstances of termination: _____

How successful do you think this method was for your child?

Very successful Helpful Not helpful

24. *Treatment and Education of Autistic and relation Communication handicapped Children (TEACCH).*

NO YES Never heard of this method.

If YES please indicate age of your child during intervention: _____

Was the intervention maintained over a long period of time and/or to completion?

YES NO. If NO please explain circumstances of termination: _____

How successful do you think this method was for your child?

Very successful Helpful Not helpful

25. *Floor Time* (Stanley I. Greenspan)

NO YES Never heard of this method.

If YES please indicate age of intervention: _____

Was the intervention maintained over a long period of time and/or to completion?

YES NO. If NO please explain circumstances of termination: _____

How successful do you think this method was for your child?

Very successful Helpful Not helpful

26. *Relationship Development Intervention (RDI)* (Steven Gutstein)

NO YES Never heard of this method.

If YES please child's age of at time of intervention: _____

Was the intervention maintained over a long period of time and/or to completion?

YES NO. If NO please explain circumstances of termination: _____

How successful do you think this method was for your child?

Very successful Helpful Not helpful

27. *Individual therapy*: NO YES Never hear of this method

If YES please indicate child's age at time of intervention: _____

Was the intervention maintained over a long period of time and/or to completion?

YES NO. If NO please explain circumstances of termination: _____

How successful do you think this method was for your child?

Very successful Helpful Not helpful

28. *Group therapy*: NO YES Never hear of this method

If YES please indicate adolescent's age at time of intervention: _____

Was the intervention maintained over a long period of time and/or to completion?

YES NO. If NO please explain circumstances of termination: _____

How successful do you think this method was for your child?

Very successful Helpful Not helpful

29. *Picture Exchange Communication Systems PECS*

NO YES Never heard of this method.

If YES please indicate adolescent's age at time of intervention: _____

How long was this communication system used? _____

How successful do you think this method was for your child?

Very successful Helpful Not helpful

30. *Assistive Technology* – meaning electrical or manual equipment used to increase, maintain or improve the functional capabilities of persons with disabilities.

NO YES Never heard of this method.

If YES please indicate adolescent's age at time of intervention: _____

Was the intervention maintained over a long period of time?

If YES how long? _____ If NO why was use terminated? _____

How successful do you think this method was for your child?

Very successful Helpful Not helpful

31. *Social Stories* (Carol Gray)

NO YES Never heard of this method.

If YES please indicate adolescent's age at time of intervention: _____

How long were *Social Stories* used? _____

How successful do you think this method was for your child?

Very successful Helpful Not helpful

32. *Gluten free –Casein free (GFCD) diet*

NO YES Never heard of this method.

If YES please indicate adolescent's age at time of intervention: _____

Question 32 continued: Do you consider this dietary method successful?

YES. Please explain: _____

NO. Please explain: _____

33. *Occupational Therapy (OT)/Physical Therapy (PT)/Speech Language Therapy(SL)* (please circle all that apply)

NO YES Never heard of this method(s).

If YES please indicate adolescent's age when intervention started and terminated:

OT _____ PT _____ SL _____

How successful do you think this method was for your child?

OT Very successful Helpful Not helpful

PT Very successful Helpful Not helpful

SL Very successful Helpful Not helpful

34. Please indicate any other clinical/behavioral/relational intervention not mentioned above your adolescent with HFA/AS has received or is receiving.

35. Is your adolescent currently attending public school? NO YES

If NO, please skip to question # 39.

If YES, please complete questions 36-38.

36. Is your adolescent under a current Individual Education Plan (IEP) at his or her present school?

NO. Please indicate why: _____

YES. Please attach goals or indicate social emotional goals and social/relational provisions made for your adolescent.

37. Are you pleased with the interventions, if any, your child is receiving in school?

NO. Please indicate why: _____

YES. Please indicate how you think interventions are benefiting your adolescent:

38. Does your adolescent with HFA/AS participate in extracurricular activities at school?

YES. What are the activities? _____

NO. No activities available.

NO. Activities available my child prefers not to participate.

39. Is your adolescent home schooled? NO

If YES: Do you manage schooling yourself? ___YES ___NO
Is schooling through a home school cooperative ___YES ___
Is schooling provided by a tutor? ___YES ___NO

40. At what grade/age did you begin home schooling? _____
_____ Please indicate why: _____

THANK YOU FOR COMPLETING THIS LENGTHY QUESTIONNAIRE

APPENDIX G1
FORMAT FOR INTERVIEW QUESTIONS FOR
PARENT/CAREGIVER INTERVIEW

1) Formal greeting. Then brief explanation of interview format and expected length of interview. “This interview is expected to take about 30 minutes. We can stop at anytime should you wish. If you do not feel like answering a question please indicate this to me. You do not have to answer any question you prefer not to. Also, if something comes to mind during our conversation that may not have been touched on, please feel free to share it. The questions I am going to ask you will center on social interactions. Part of the interview questions will focus on social interactions around your child’s ability to function within the home and community with regards to managing day to day adaptive functions. The other part of the interview questions will focus on your observations and experiences regarding your child’s social relationships with peers around his or her age. Do you have any questions before we begin?”

- 1) To begin with tell a bit about your experiences of having a child with HFA or AS..
- 2) Explain to me about your child’s ability to relate to family members at this present time and how has this changed over time?
- 3) As we all grow and mature there are certain skills and activities we learn either through being told or by observation. These skills and activities are necessary for our caring of self and others as well as for interactions within the social community. Please share how you view your child’s abilities and coping skills within this context particularly as it pertains to his or her current age.
- 4) Now that your child is of middle school age please give me your prospective of his or her relationship with peers and how he or she spends his or her leisure time.
- 5) Can you tell me about any concerns and hopes for your child’s future?

In closing the participant parent/caregiver will be thanked for their time. They will also be reminded that on completion of all interviews and when the researcher has compiled all results these results will be available for any parent/caregiver to review upon request.

APPENDIX G2
FORMAT FOR INTERVIEW QUESTIONS FOR
ADOLESCENT INTERVIEW

1) Formal greeting. Then researcher will make sure the adolescent is comfortable about being video taped and is sure about taking part in the interview. A brief explanation of interview format and expected length of interview will be given. “This interview is expected to take about 30 minutes. We can stop at anytime should you wish. If you do not feel like answering a question please indicate this to me. I will ask you occasionally if everything is OK. You do not have to answer any questions you prefer not to. Also, if something comes to mind during our conversation that may not have been touched on, please feel free to share it. The questions I am going to ask you will center on social interactions. Do you have an idea about what social interactions are? [If NO process of a social interaction will be explained. If YES explanation of interview format will continue.]

Part of the interview questions will focus on social interactions around how you interact with your family at home and what you do in the community where you live. The other part of the interview questions will focus on your observations and experiences regarding friends at school or out of school. Do you have any questions before we begin?”

- 1) To begin with tell a bit about what you know about High Functioning Autism/Asperger’s Syndrome.
- 2) As we all grow and mature there are certain skills and activities we learn either through being told or by observation that make us more independent and able to look after ourselves. Tell me how looking after yourself has changed or is the same as when you were a little younger than you are now.
- 3) How do you like to spend time with your family?
- 4) Do you like going out into your community to do things?
- 5) Now that you are in middle school do you still have friends from previous grades?
- 6) Do you have any new friends?

7) Do you have any concerns about the future? Tell me some of the things you would like to do.

In closing the participant adolescent will be thanked for his or her time. They will also be reminded that on completion of all interviews and when the researcher has compiled all results these results will be available upon request.

The research interviewer will also debrief the adolescent by asking how he or she is feeling now the interview is over and if there are any questions or concerns.

APPENDIX H

THE ADOLESCENTS' PRESENTATION DURING THE INTERVIEW

Fictitious names have been given for reasons of confidentiality.

Richard, age 15:6

Richard came into the room and took a place as close to the left hand side of the settee as possible. This actually placed him closer to the researcher. He sort of hunkered himself up into the corner of the seat with his arms folded in front of him. His face showed no emotion and his eyes held no spark and there was minimal eye contact with the researcher.

As the researcher started the interviewing process, a flicker of connection went across Richard's face. Richard's verbalized his understanding of what was being asked with mumbles of yes. As he interacted he took quick glances into the video camera.

When asked if he understood social interactions he made no verbal comment but gave an affirmative nod of the head and again a quick glance into the camera.

Tenseness in Richard's physical self was noticed. He rocked a little on occasion. As the interview proceeded, Richard unfolded his arms. He pulled at his watch strap and occasionally rubbed his hand over his hair and then across his face. His head was tilted with his chin towards his left shoulder. Richard answered the questions in a coherent and contextual manner.

Richards demonstrated no verbal fear of answering the questions. His quality of voice was monotonic with a nasal quality. Richard kept his voice at a low level of volume throughout the interview.

One of the researcher's questions was wordy. Richard asked for it to be repeated. The researcher asked the question again with longer pauses. Richard indicated after each pause that he understood what was asked by giving the researcher a nod.

Once the meaning of the question has been grasped Richard's, response was clear and appropriate although intermittently he cleared his throat. Richard's physical reaction does not match his succinct responses. He twisted his hands and fiddled with his wristwatch. At one point Richard stopped fiddling and twisting his hands and used them to emphasize something he was saying.

Technical difficulties interrupted the conversation and the researcher left her seat to attend to the problem. Richard resumed his folded arms posture, and looked off to the right with no show of emotion or inquisitiveness on his face.

During the times when Richard was not talking his mouth remained in a slightly open posture.

As the interview was obviously coming to an end through the comments made by the researcher, there was a change in Richard's observed bodily tension. He seemed to relax more. He stopped fiddling with his watch, and refolded his arms as they were when he first sat down. When the interview was over, Richard intimated the interview was shorter than he expected but confirmed he felt OK about the process. Richard was quick to get up off the seat, and put on his jacket as he left the room.

Christine, age 18:2

Christine entered the room and sat on the section of the two-seater chair furthest away from the researcher. She sat with her knees together and her toes pointing inwards with her hands resting on her knees. Her expression had a blank but annoyed quality to it.

As the researcher moved around making the final set up, Christine's eyes did not follow the researcher but her eyes fell on the objects the researcher was working with – i.e. tape recorder.

As the conversation began and Christine was informed there have been others before her, a smile emerged on her face, and she lifted her head up a little and looked towards the researcher. Christine placed her hands between her knees and seemed to be more engaged in the process.

Christine's voice carried a continuous monotone. It was loud and got even louder when any content in the conversation touched on an excitement or concern. She also clapped her hands together to emphasize her feelings about something.

Christine responded to questions in an abrupt fashion and used a minimum amount of words for any reply. She nodded and added a verbal OK on occasion indicating she understood what was being said.

Christine often verbalized she did not understand a question. However, before the question was repeated, Christine began to answer the question. She often lent forward and answered the question.

During more pensive moments, Christine put her left hand under her chin and half smiled.

Christine used her hands to emphasize her replies. Her replies were short and to the point – sometimes only a yes or no was offered and when pressed for more input she still stuck to a short answer.

When she explained a difficulty she had with a potential beginning friendship a big grin crossed her face. This was an example of disconnect between situation and emotional presentation regarding the situation. Another example of this was as she talked about a food she liked her facial expression was a grimace rather than a show of delight.

Christine's tone softened when she talked of friends in the past and the present. Her voice also trailed off – losing some of its monotonic flavor and loud presentation.

When she talked about something that seemed to cause her some anxiety she pulled at her hands and intertwined her fingers.

When saying something she seemed proud about or when emphasizing something she did not seem to like, she clapped her hands together.

Christine demonstrated some coyness and connection with the camera by grinning, looking directly into the lens and then averting her eyes. The topic at this point in the discussion was her ability to manage chores.

Christine appeared relaxed throughout the interview and verbalized she was comfortable about doing it.

James, 17:3

James came into the room and took a seat at the right hand side of the settee and to the left of the researcher. Although this placed him further away from the researcher James turned his body in her direction.

James listened to the researcher with his eyes flitting glances at her and with an open yet emotionless expression on his face. He let the researcher know he understood what was being said as he gave brief nods. Sometimes a brief and pleasant smile crossed his face. James' voice was monotonic. He tended to draw out his words and his pronunciation was labored. James' articulation was not within the norm and the volume of his voice was loud.

When James answered questions his face changed from the open but emotionless presentation to incorporate little smiles and looks over the top of his glasses. He also gave quick glances to the upper right, and used his hands to emphasize some of his statements.

As the interview progressed, James demonstrated a modicum of discomfort. He rubbed his head with his hand and moved his shoulders around.

James was not very voluble. He replied to questions using the minimum amount of words necessary. He tended to nod in answer to questions and needed cues to maintain the reciprocal process of the interview.

Nigel, 15:4

Nigel's interview took place in his home at the request of the parent. There were conversations going on in the kitchen that could be heard on the video tape – although not at a distracting level. As the researcher checked the video camera, Nigel showed no interest or inquisitiveness in what the researcher was doing. He was in his own world. Nigel sat on a comfortable sofa with his dog by his side for much of the interview.

Apart from a loving and brief smile to the dog, Nigel did not defer to his pet during the interview. Although he kept his arm around the dog and stroked him.

Nigel looked towards the researcher as she asked questions. His face looked peaceful but his eyes had no “brightness” in them or look of connection. Nigel wore glasses and needs to at all times. However, when Nigel answered questions there was a different more engaged expression in his eyes. Also, when his dog cuddled up Nigel’s face and eyes brighten up completely.

When there was a technical hitch with the video camera, Nigel demonstrated more overt facial connection but as soon as the business of listening to the interview questions started, his face reverted to a bland look.

Nigel used hand gestures to emphasize what he was explaining. He stretched out a laugh when he made a little joke about something. His voice articulated, clear and with some intonation. The volume of his voice was loud. He used the filler “errr” quite often as he linked one spoken thought to another.

Yet another technical problem occurred. Nigel got up from the sofa and wanted to help the researcher. He suggested a swift kick might help and laughed a drawn out almost theatrical laugh.

Nigel either leaned back comfortably in the sofa or moved forward towards the researcher as he explained something. When he shared his thoughts he seemed self-reassured with regards to his presentation and content.

Charles, 17:4

As the researcher prepared for the interview, Charles took a seat. He sat in the center of a two-seater couch. He tapped his feet, left, than right continually for about 98% of the interview. He folded his arms in front of his tummy and held his sleeves with his hands and sometimes moved his thumb in a nervous manner. Charles looked around the room with fleeting glances at all the objects.

As the researcher began the interview, Charles turned his face towards the researcher. But as the conversation continued, Charles alternated from looking at the researcher and than away. When he looked away he always turned his head to the right as he replied. Apart from the feet tapping, Charles incorporated other movements. He jerked up his elbow or lifted his glasses to rub his eyes.

Charles had a sweet and open demeanor. His face demonstrated an interest and receptiveness to the questions. He nodded to indicate he understood what was being said. Charles voice tone and intonation were within normal limits tinged by a continuous excitement. He spoke clearly and within the context of the ongoing interview.

During the conversation Charles used his hands a lot to emphasize what he was saying. When he talked about being a younger child and crying he balled up his fists and rubbed his eyes. When he used a number for an example he used his finger to show the count. His facial expression was one of engagement. His demonstrated an enthusiasm about what he was talking about.

When he began to talk about his good friend, his body seemed to settle and he did not move around so much. Despite Charles physical activity during the interview he waited

his turn to speak. When the topic of the conversation moved to what seemed an anxiety provoking one for him, Charles intertwined his fingers. He was cheerful throughout the entire interview and said he enjoyed talking and was comfortable with the process. When the researcher reviewed the video after Charles had left, Charles was seen making a victory sign into the lens before he left the room.

Donald, 18:2

Donald came into the room with in an upbeat energetic manor. He sat in the center of the two-seater chair but quickly got up to see if he could help the research prepare the video camera. His desire to help the researcher my have been because the research was mumbling away about getting the video prepared, which in fact was running anyway. Donald sat down when things were ready to go. He rested his right ankle on top of his left leg. This gave him the opportunity to pull at the rubber toe of his sneakers with his right hand as he cradled his chin with his other hand and surreptitiously nibbled at his fingers between answering questions. Donald had a sweet and nervous demeanor. He told the interviewer he tends to cry. His face turned towards the researcher as she began to ask questions but the video tape shows, Donald's eyes darting in different directions as he voiced understanding of the questions with "Umms" and "OKs" and other little agreeable noises. Despite the fact that Donald's eyes were darting around during the questions he understood the questions and his manner of verbal communication was clear, well toned and within the context of the question. He liked to use metaphors to explain himself and recognized that it might seem he was going off topic but noted he would get back to the question.

During a technical hitch when the researcher had to get up to check the camera, Donald took the opportunity to smile and wave at the camera.

Donald used hand and body gestures to reaffirm what he said. If he spoke about someone tapping their feet, he tapped his feet. If he mentioned others looking at their watches, he looked at the place on his wrist where a watch could be. He also mimicked how someone showed him they were not interested in him or his conversation.

When the conversation touched on something that seemed to concern him, Donald's hands left the area of his mouth and he began to interweave his fingers. This happened during a verbalization of a fear about taking on responsibility. He also looked down and gave a nervous chuckle.

Occasionally, after Donald explained something he added an intake of breath and an exhaled little "Yeah" after finishing a statement. The researcher, when working with other young people who were having emotional difficulties, not necessarily any with a diagnosis of HFA/AS, would let a breathless "Yeah" terminate their spoken thoughts. The "Yeah" seems to carry a connotation of "that's the way it is..."

On one occasion Donald's voice drifted off. He seemed a little confused. He tapped the right side of his head and said he was losing track. He brightened up and said he remembered and carried on.

Donald shared honestly what he saw as his faults. On one occasion when he talked about forgetting things he should do at home he looked into the camera and said; "That's how hopeless I am."

Donald used little soft “umms” as fillers as he strung one thought to the next. He was excited about participating in the interview and shared he liked to talk a lot.

George, 19:6

George came into the room and chose to sit on the right hand side of the two-seater chair which placed him to the left of the researcher. He asked if he could set up his laptop. He placed the laptop on his knees and proceeded to set it up as the researcher moved around checking on the equipment.

George’s forehead was furrowed. He paid no attention to the researcher. As the researcher began the interview, George lifted his head and looked at the interviewer with the same concentrated look given to his computer as he set it up and with the same furrowed brow.

The researcher began the introductory protocol of the interview and went into the first question. George nodded in a pontificating manner to demonstrate he understood the content. He had a serious and almost benevolent look on his face. As George listened he brought his left finger up to his lip in pensive mode. His facial expression was intense as if he was really trying hard to be engaged in the process.

Although, George’s forehead was furrowed his body language indicated a relaxed mode. He sat back in the chair with the computer open and resting on his knees. He stretched out his left arm to rest on the back of the two-seater chair.

George’s facial expression remained intense giving the indication he was giving a great deal of thought to his answers. As George answers his eyes look to the right. He used his

hands to emphasize a point he was making bringing them above the computer so that the researcher was able to see them.

George was very articulate in his responses and tended towards intellectualizing the answers. He seemed to want to be connected to the researcher. Almost every time after he had finished his answer it was as if a switch had gone off in him. He looked down at his computer was silent and momentarily seemed disconnected until the researcher spoke again.

George was very formal throughout the interview. He maintained a serious demeanor. When he shared some concerns about anxiety and/or tension and how he handled it, he brought his hands over the top of the computer and showed the researcher where he had bitten or struck his fists.

George's quality of voice was not monotonic but the volume was low and he rolled the sounds of the words around in his mouth, emphasizing the 'r' sound.

From the expression on his face, George put a lot of thought into his answers. When talking about the concern his mother had about his condition he kept the computer solidly in front of him as he stretched and rubbed the top of his head with his hand. When George talked about something which seemed to touch him emotionally he brought his hands to each side of his laptop and tapped his fingers.

As the interview proceeded George slipped in a yawn here and there.

When the researcher made some speculative comment with which George did not necessarily agree a half smile crossed his face.

At the end of the interview George was asked if he had a question to ask. He became very interested in this. He closed his laptop, put his hands together and rested them on top of the laptop and lent forward towards the researcher. His face lit up, and there was no more furrowed brow.

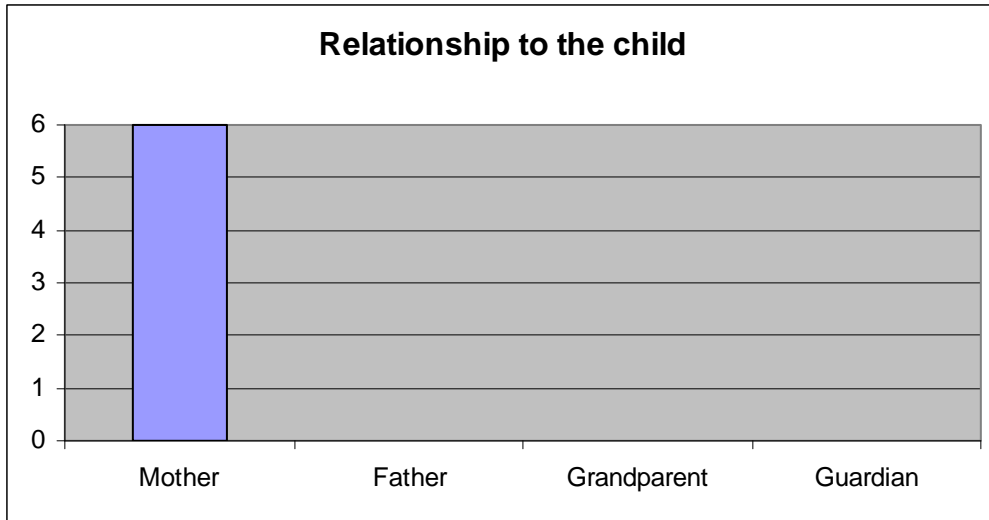
At the end of interview as the interviewer left her seat to shut off the video camera, George looked towards the camera and seemed to mouth something, which even after several reviews the researcher was unable to decipher. He then raised his eyebrows and smiled.

APPENDIX I

CHARTS

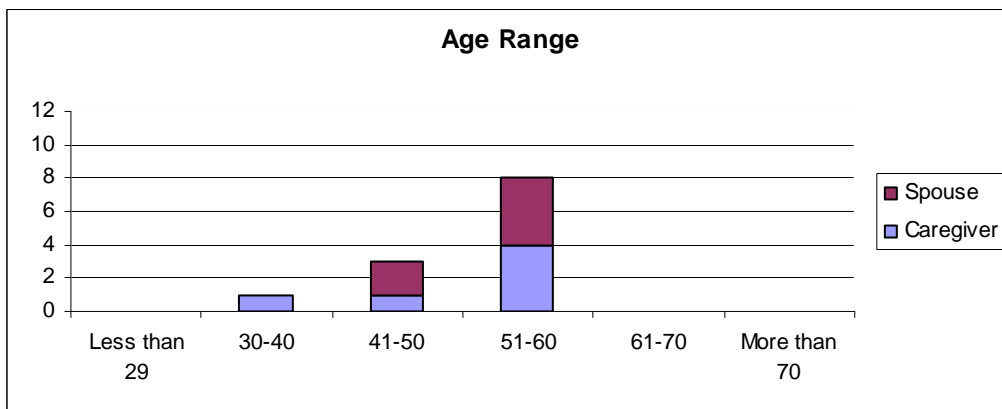
Mother	6
Father	0
Grandparent	0
Guardian	0

Question #2



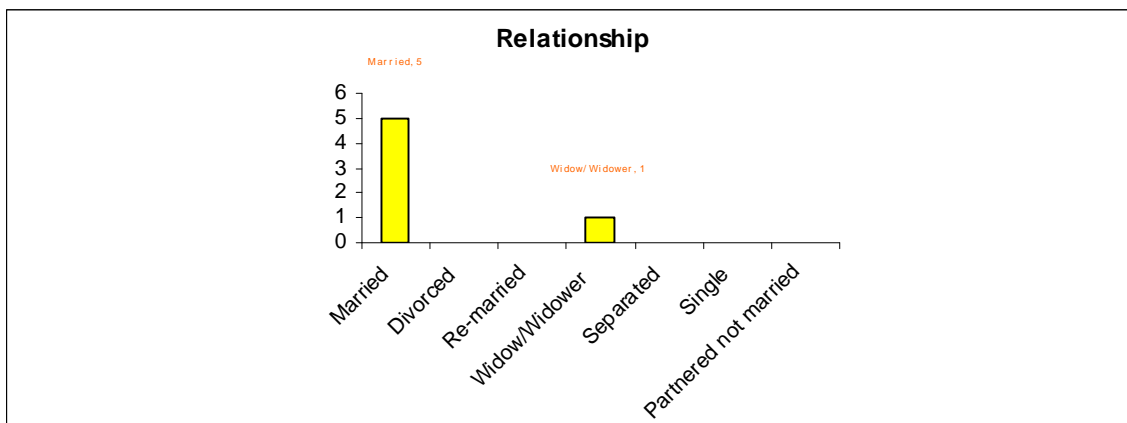
Age Range	Caregiver	Spouse
Less than 29		
30-40	1	
41-50	1	2
51-60	4	4
61-70		
More than 70		

Question #3



Relationship	
Married	5
Divorced	
Re-married	
Widow/Widower	1
Separated	
Single	
Partnered not married	

Question #4



Question # 5: Race/Ethnicity – All participants Caucasian

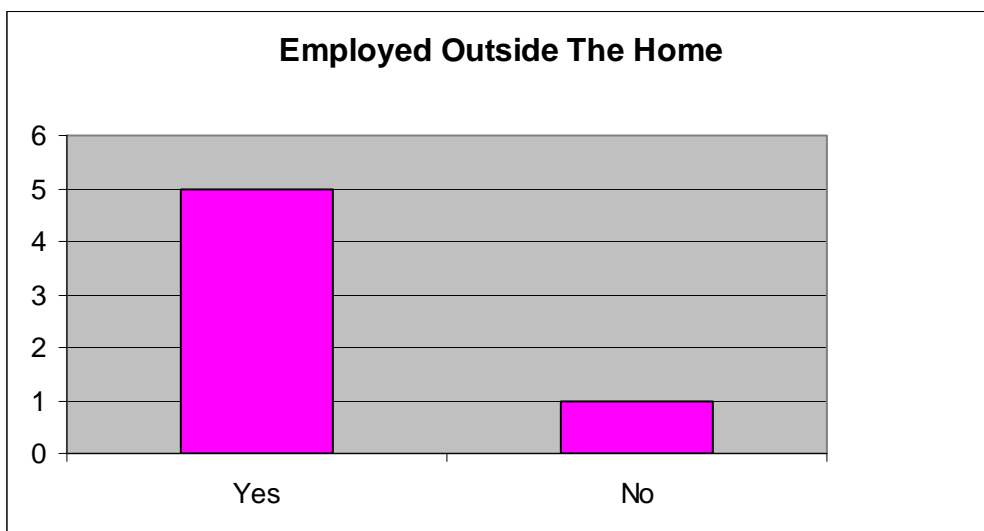
Question # 6 & 7: Education

Education	HS Diploma	GED	Some College	4 Year Degree	Graduate Degree
Spouse			1	3	1
Caregiver				2	1
Guardian			0	0	0

Question # 8 & 9 & 10

Parent/Caregiver -Employed Outside The Home All spouses employed outside of home

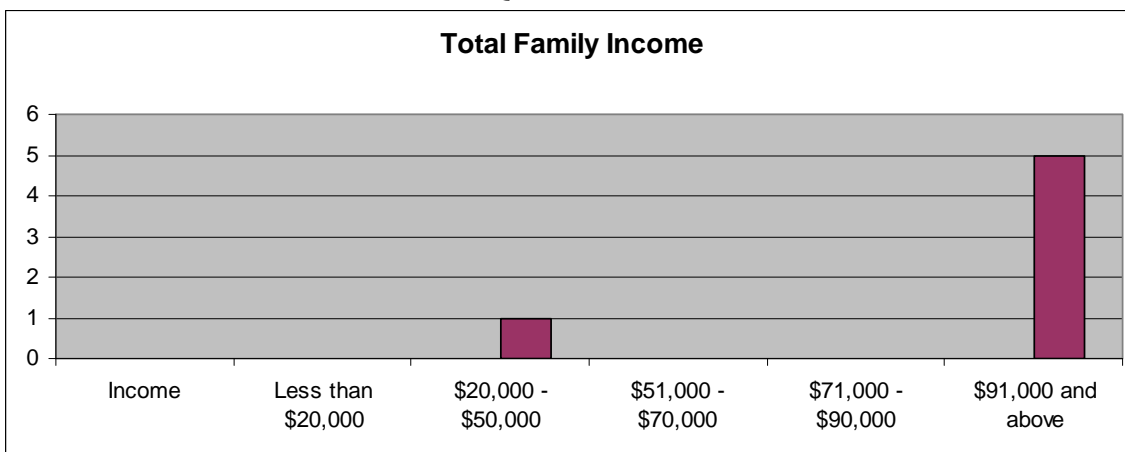
Yes	5
No	1



Income

Less than \$20,000	
\$20,000 - \$50,000	1
\$51,000 - \$70,000	
\$71,000 - \$90,000	
\$91,000 and above	5

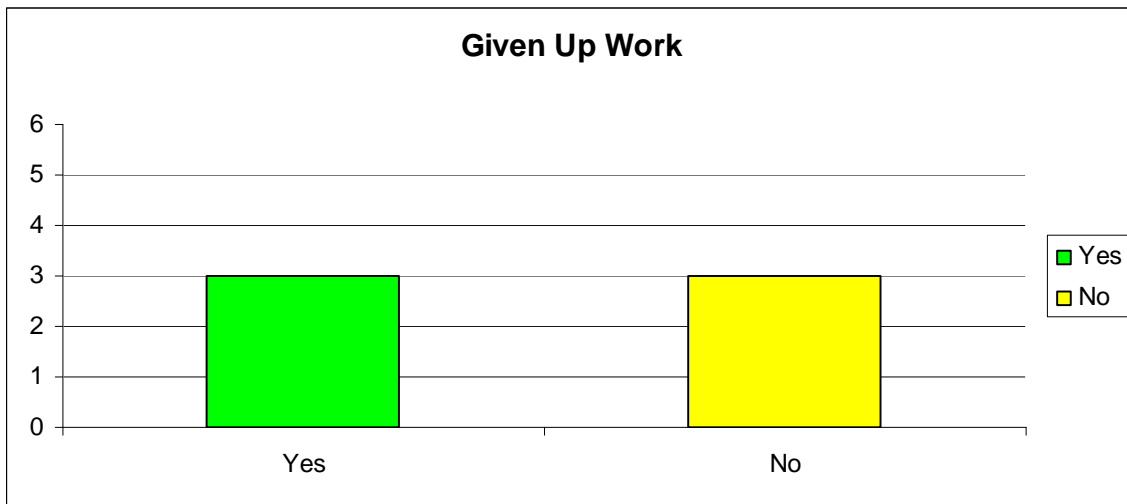
Question #12



Given Up Work

Yes	No
3	3

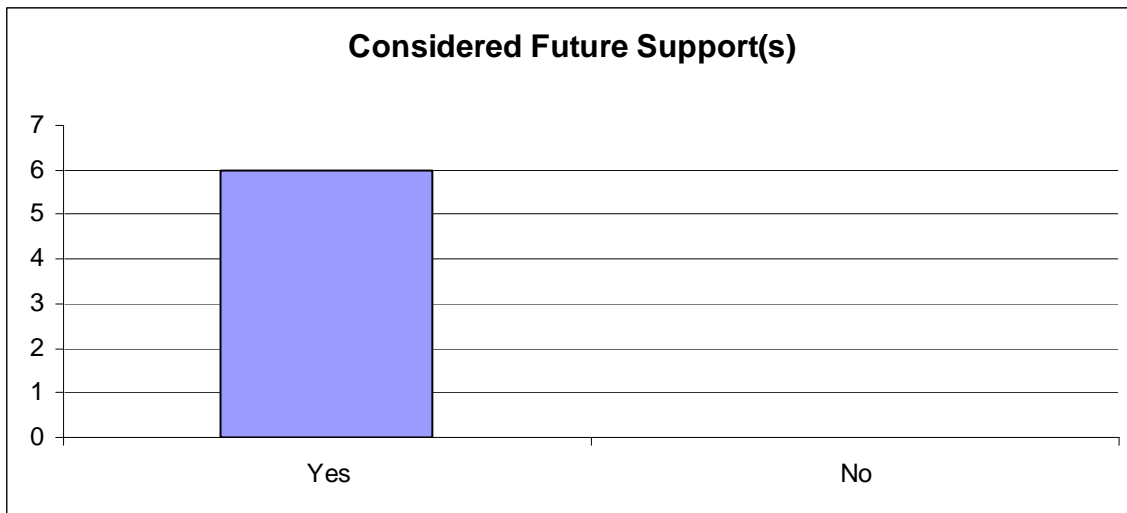
Question #13



Considered Future Support(s)

Yes	No
6	0

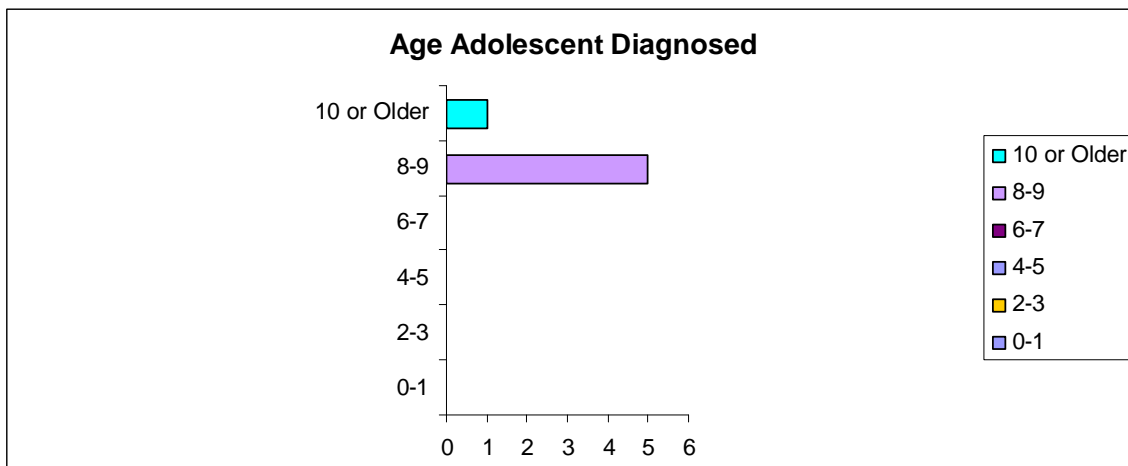
Question #14



Age Adolescent Diagnosed

0-1	2-3	4-5	6-7	8-9	10 or Older
				5-Jan	1

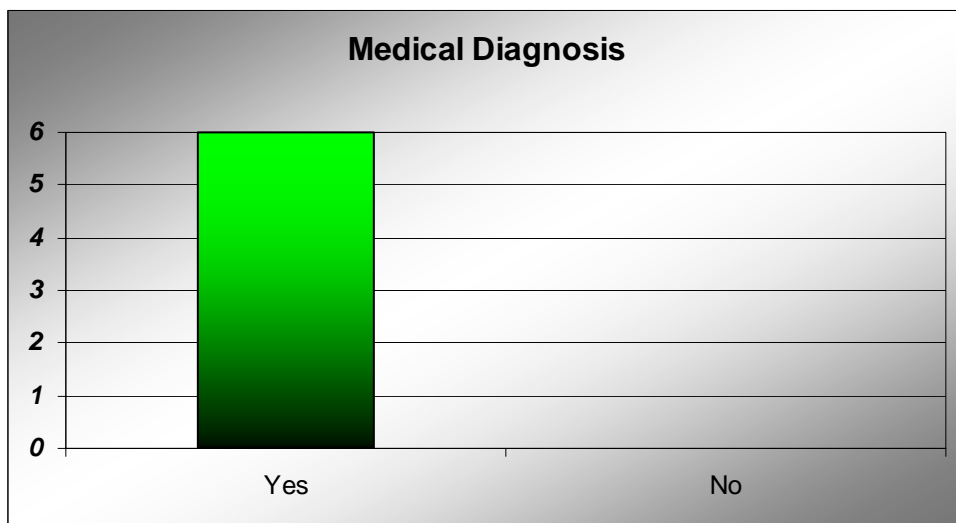
Question #15



Medical Diagnosis

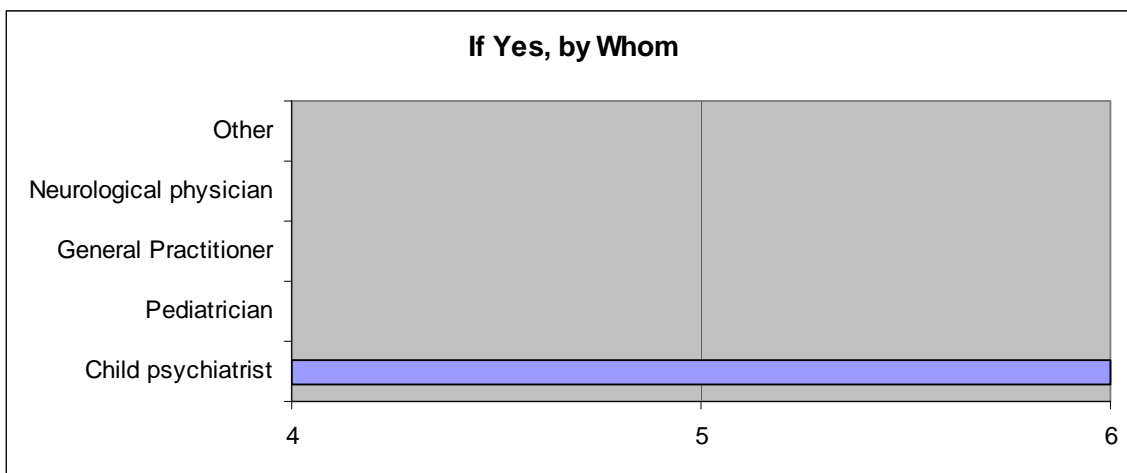
Yes	No
6	0

Question #16



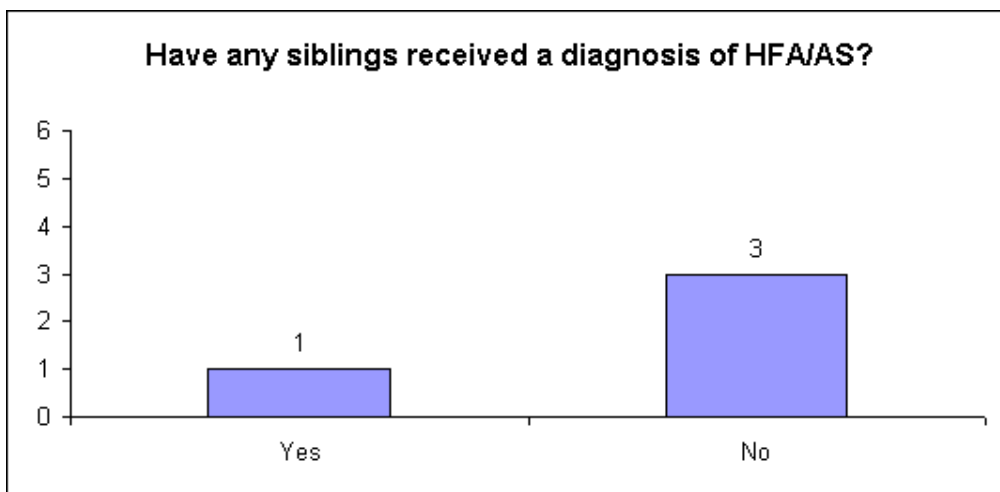
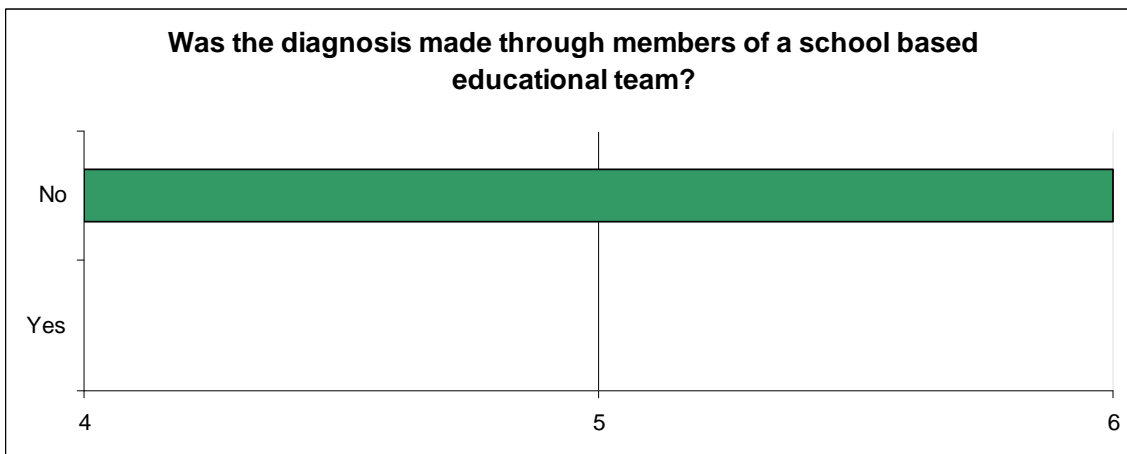
If Yes, by Whom

Child psychiatrist	Pediatrician	General Practitioner	Neurological physician	Other
6	0	0	0	0



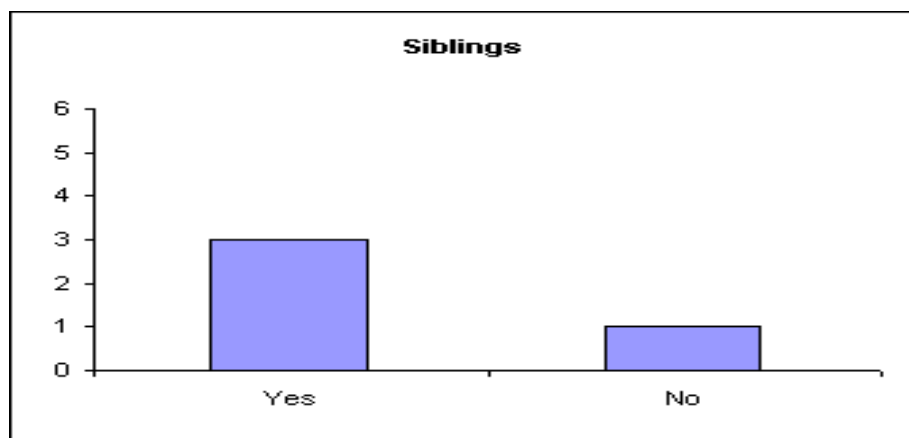
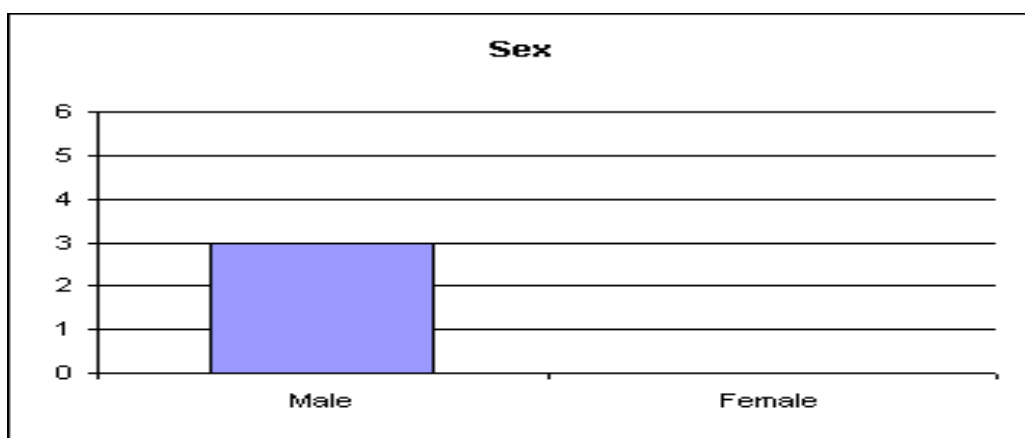
Was the diagnosis made through members of a school based educational team?
 Yes No

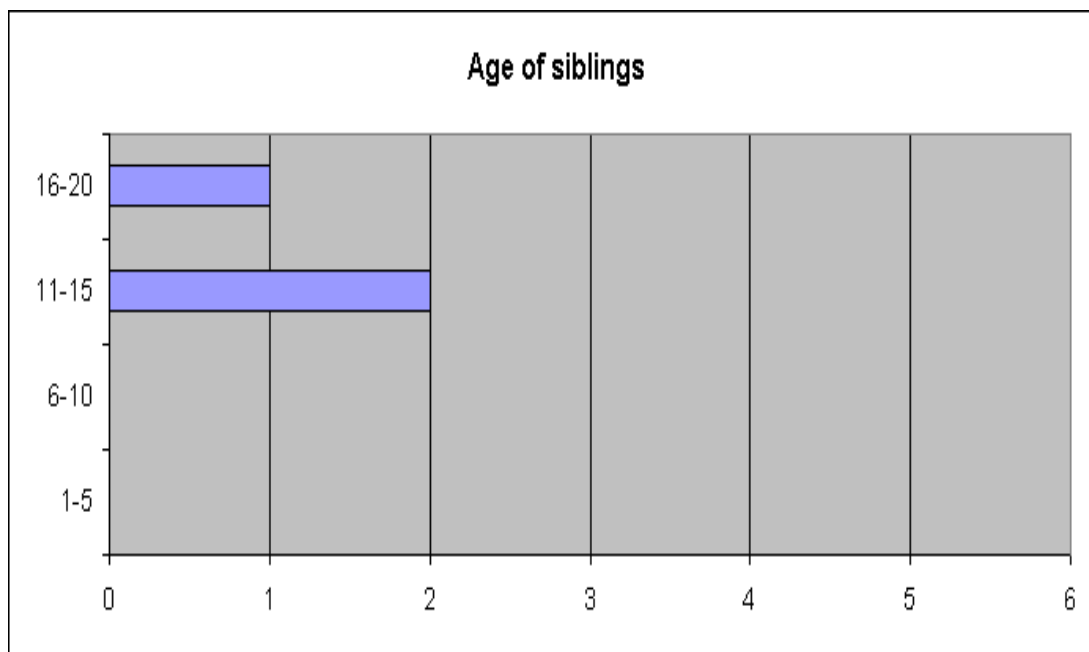
Question #17



Siblings			
Yes	No		
3	1		
Sex			
Male	Female		
3			
Age			
1-5	6-10	11-15	16-20
		2	1

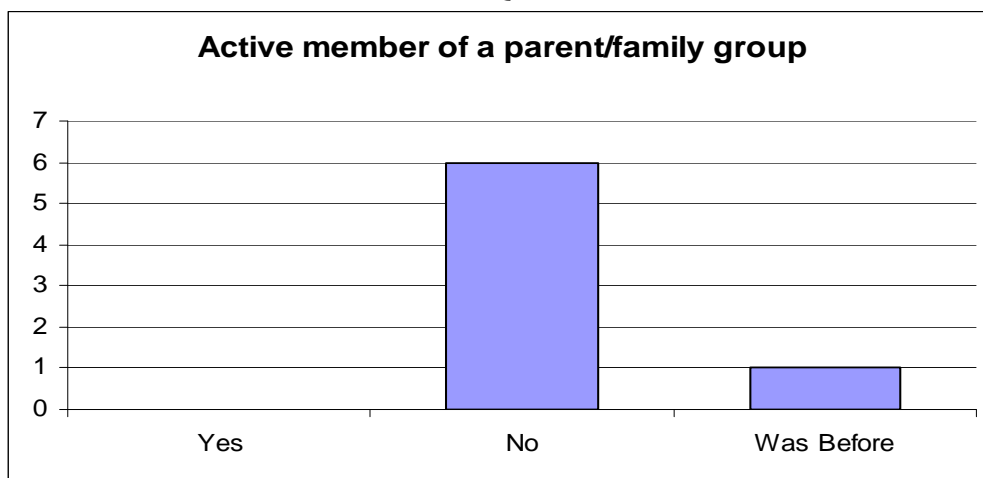
Question #18





Active member of a parent/family group
 Was
 Yes No Before
 6 1

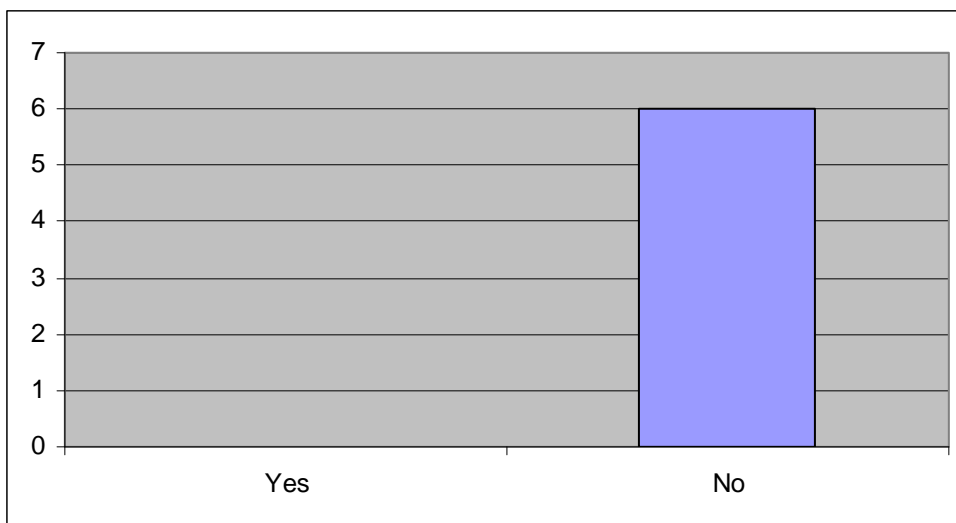
Question #21



Any family member active in a HFA/AS support group?

Yes No
 6

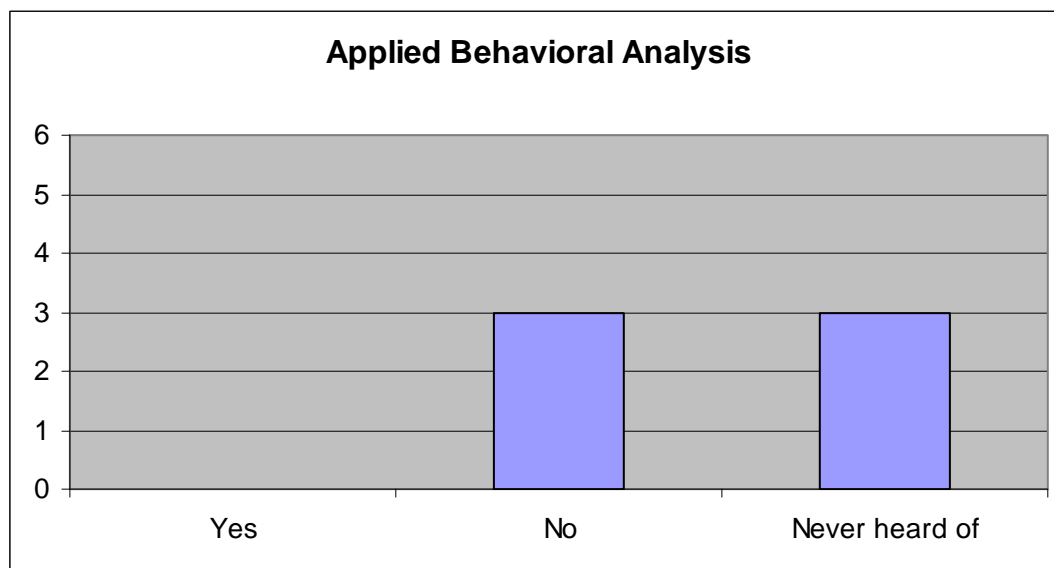
Question #22



Applied Behavioral Analysis

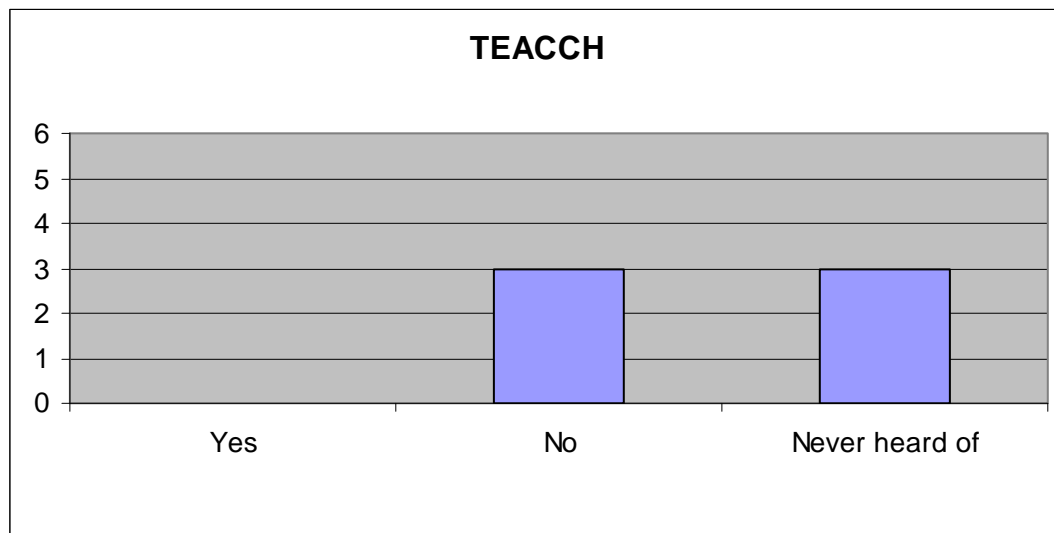
Yes No Never heard of
 3 3

Question #23



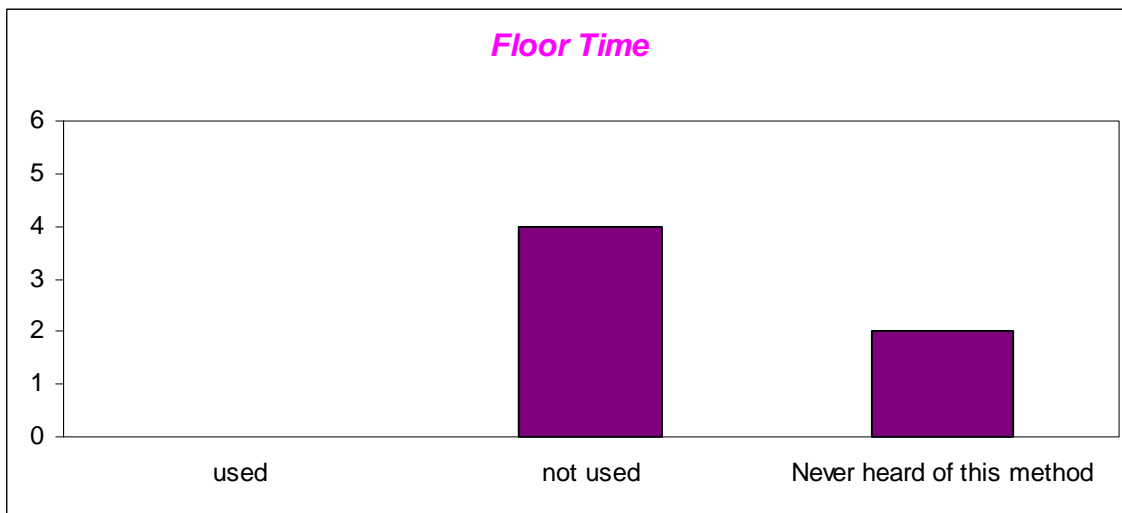
TEACCH
 Used not used Never heard of
 3 3

Question #24



Floor Time
 used not used Never heard of this method
 0 4 2

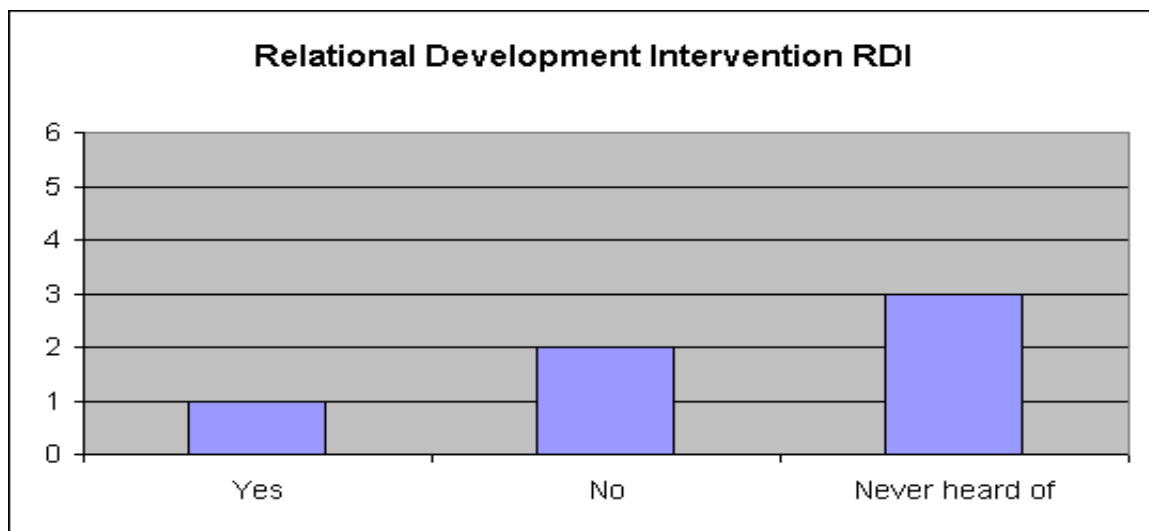
Question #25



Relational Development Intervention

Yes	No	Never heard of
1	2	3

Question #26



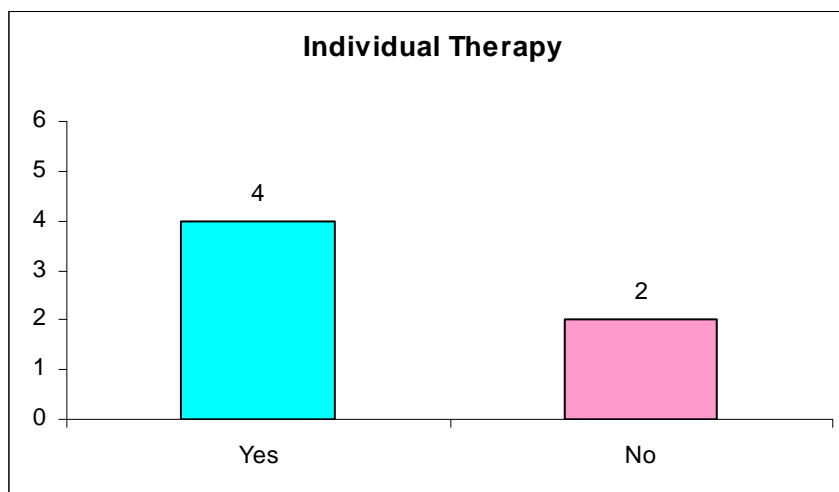
Individual

therapy

Yes	No
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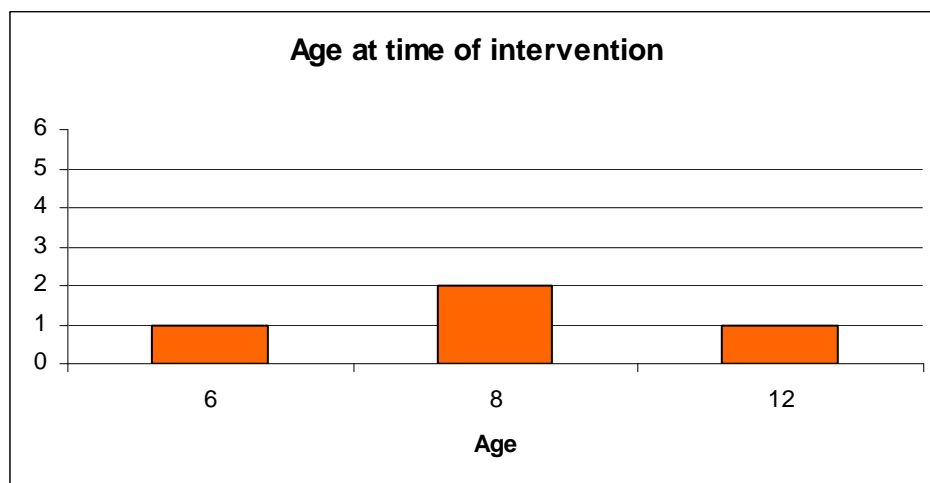
4	2
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Question #27



Age at time of intervention

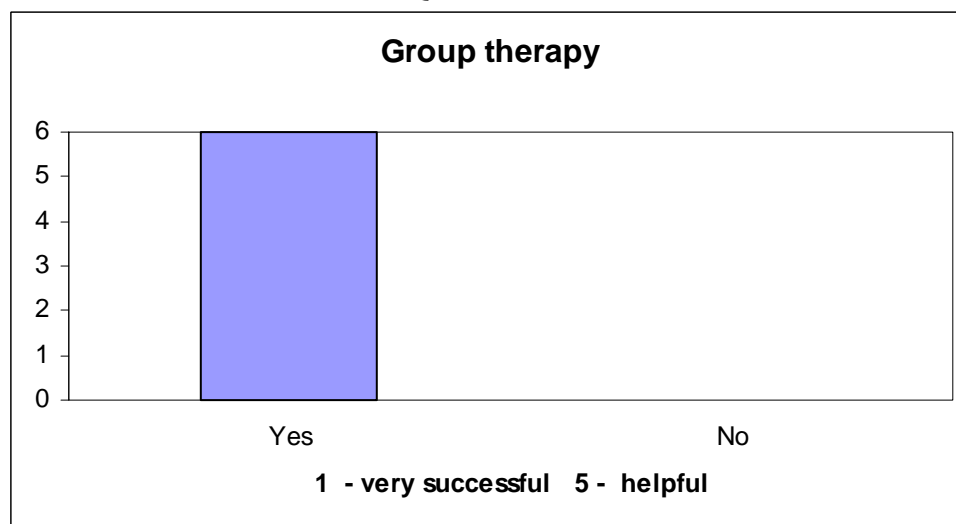
6	8	12
1	2	1



Group Therapy

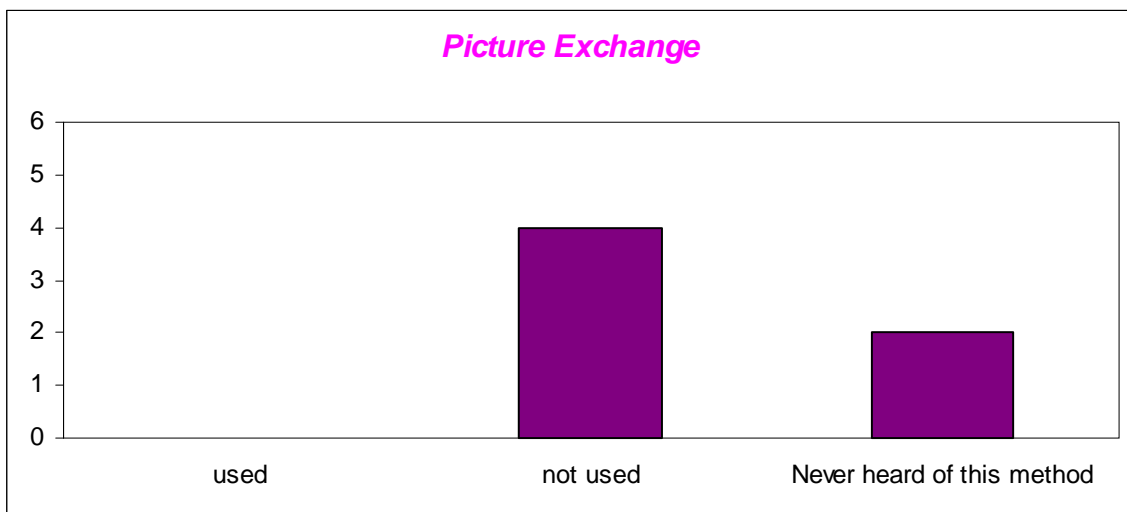
Yes	No
6	0

Question #28



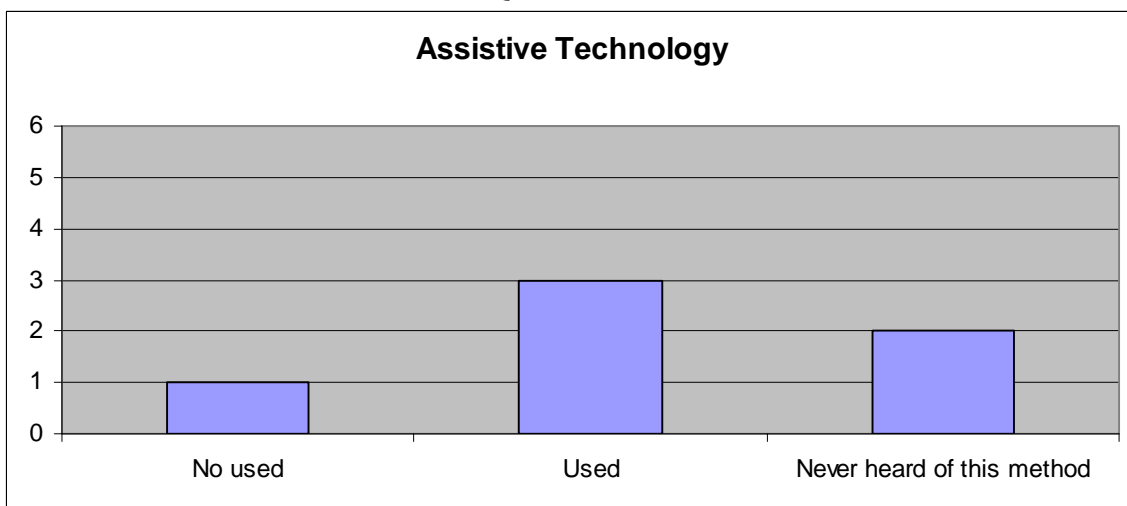
Picture Exchange
 not used Never heard of this method
 Used used method
 0 4 2

Question #29



Assistive Technology
 No used Used Never heard of this method
 1 3 2

Question #30

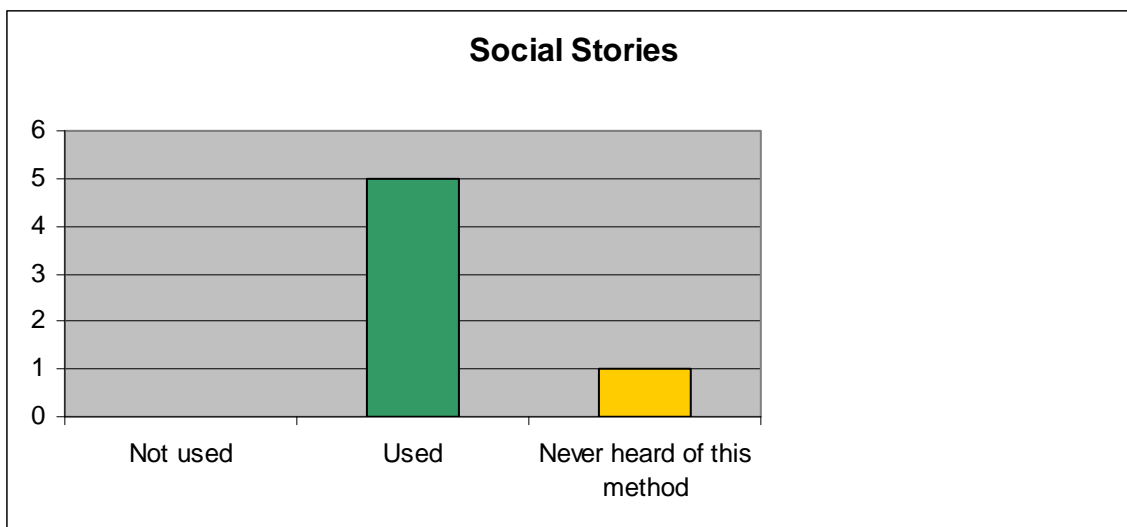


Social Stories (Carol Gray)

Not used	Used	Never heard of this method
	5	1

- 1-Age 10 for 2 years
- 1-2nd - 8th grade = 6 years
- 1-Age 15 for 2 years

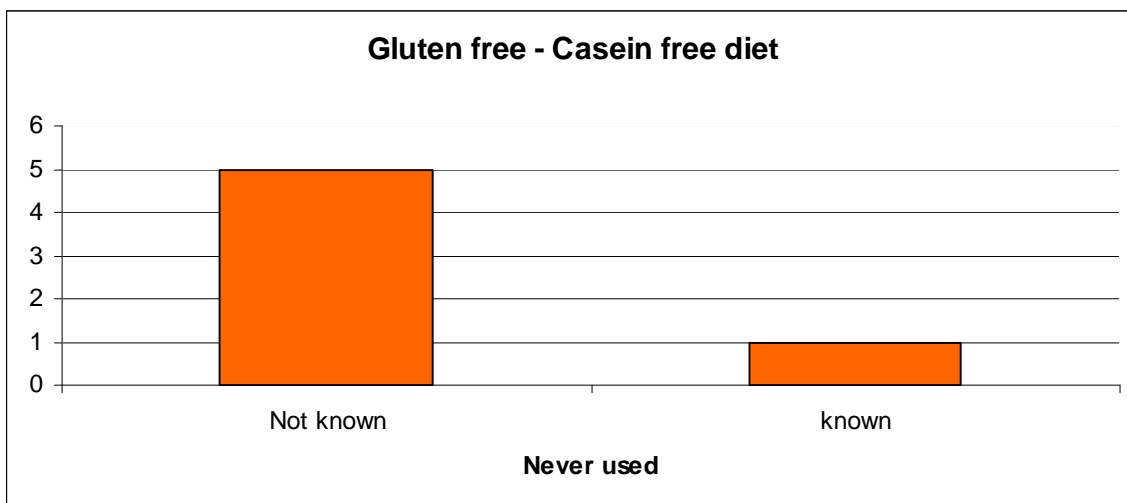
Question #31



Gluten free - Casein free diet

Not known	known
5	1

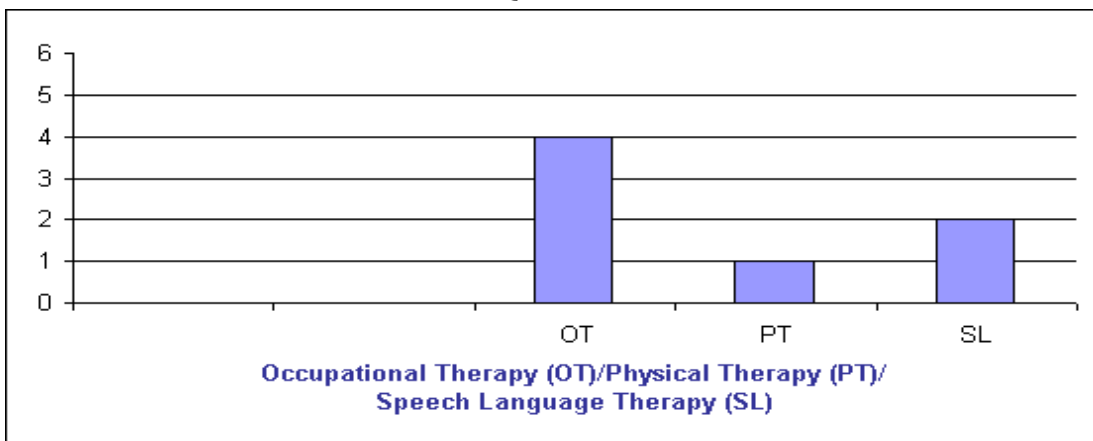
Question #32



Occupational Therapy /Physical Therapy/Speech Language Therapy

OT	4
PT	1
SL	2

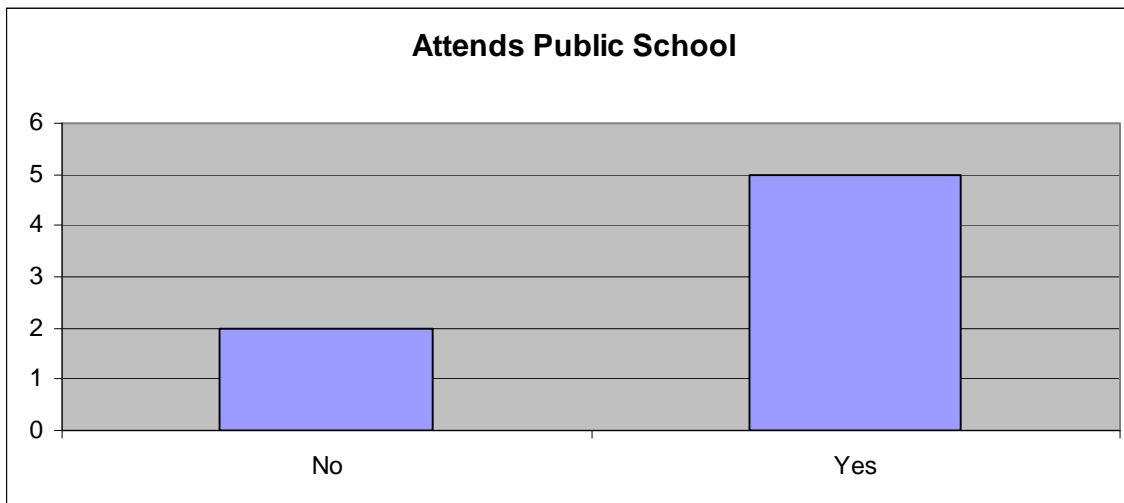
Question #33



Attending Public School

No	Yes
2	5

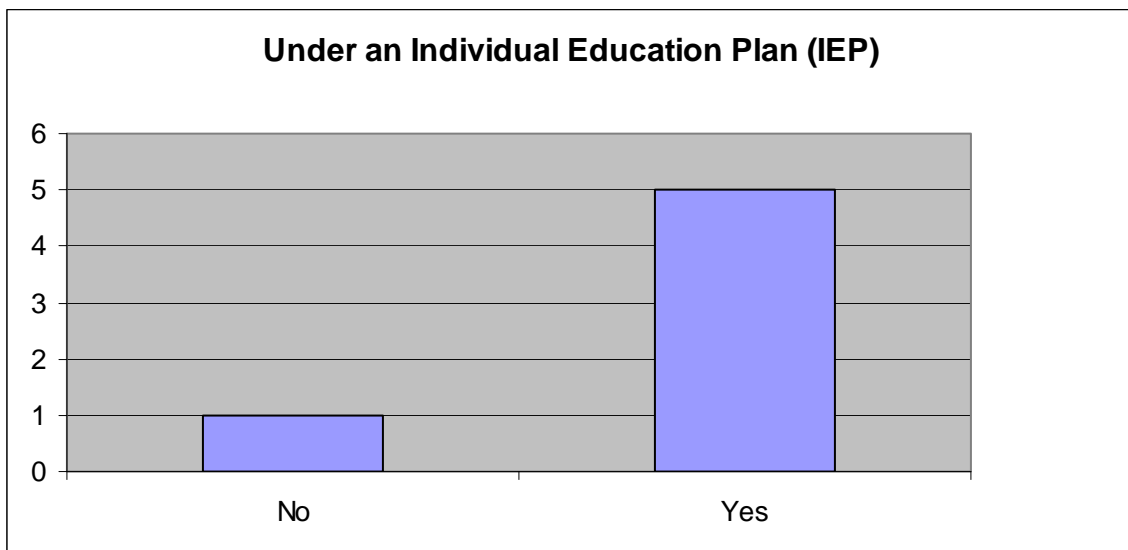
Question #35



Under a Individual Education Plan (IEP)

No	Yes
1	5

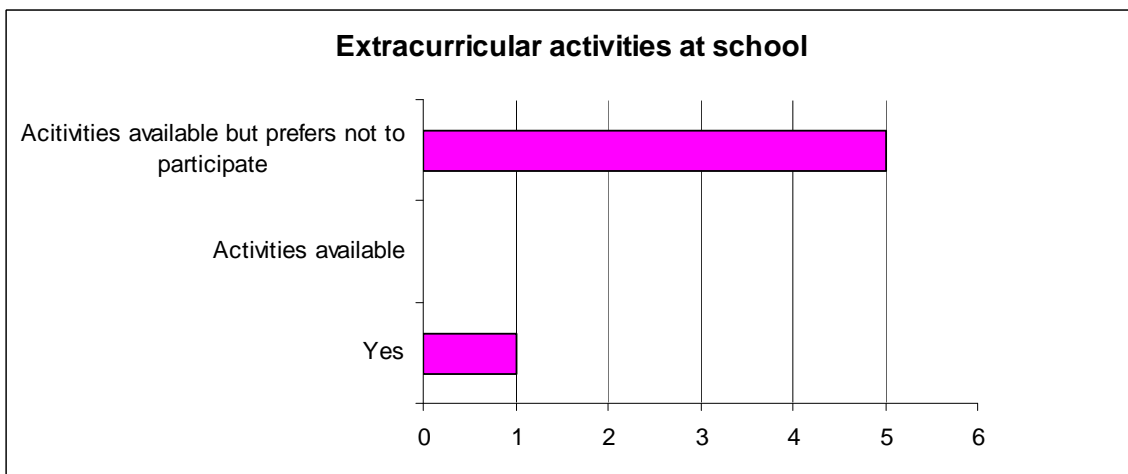
Question #36



Extracurricular activities at school

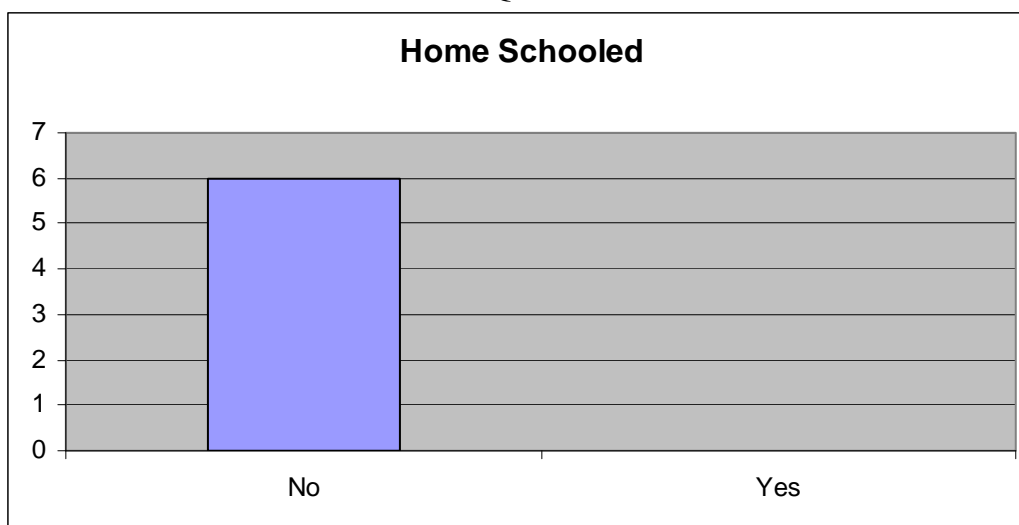
Yes	Activities available	Activities available but prefers not to participate
1	0	5

Question #38



Home Schooled
No Yes
6 0

Question #39



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VITA

Patricia A. Kunz, LCSW completed the degree of Doctor of Philosophy in Clinical Social Work at Loyola University Chicago in December 2009.

She earned her Masters in Social Work, majoring in School Social Work, at the University of Illinois, Urbana-Champaign on June 1999, and was awarded a Bachelor of Arts at University of Illinois, Chicago on July 1993 with a double major in psychology and sociology.

While working for her Masters degree, P. Kunz taught in the capacity of substitute teacher in both short and long term assignments. On her graduation in 1999 she took a position at a middle school as a school social worker and continues in this position to date. In addition to working with middle school students' ages 10 to 14 she works with students in Kindergarten through fourth grade.

In the summer of 2000 to the spring of 2002, Patricia completed her doctoral preceptorship at Psychiatric Unit, College of Medicine, UIC in Rockford, Illinois during which time she worked with individual adults, both male and female, married couples and was an assistant therapist in groups for children with high functioning autism and Asperger's Syndrome. On completing her preceptorship and gaining her License in Clinical Social Work she was asked to take on a part time position as a psychotherapist at the College of Medicine and continues in that capacity to date.

Patricia has conducted seminars on the topic of persons with High Functioning Autism and Asperger's Syndrome.

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The final copies have been examined by the director of the dissertation and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the dissertation is now given final approval by the committee with reference to content and form.

The dissertation is therefore accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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