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Early identification of children with Asperger Syndrome: Communication characteristics

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Early identification of children with Asperger Syndrome: Communication characteristics

Abstract
Diagnosis of children within the Autism Spectrum Disorder (ASD) category varies significantly but children with Asperger Syndrome (AS) are typically diagnosed at a much older age than those with Autism (AD). The late childhood diagnosis of AS means a possible lapse in years that the child receives appropriate intervention and support. The purpose of this retrospective study was to gain further insight into what early communication and behavior characteristics can be identified in children from birth to three years who are later diagnosed with AS.

Parents of ten children with AS and under nineteen-years old were identified to participate in the study. The subjects’ parents answered The Rossetti Parent Questionnaire and participated in face-to-face, open ended question interviews regarding their children from birth to age three. Parents were encouraged to share early memories about their child’s communication and behavior.

The results of this investigation indicate that evaluating behavioral and communication characteristics of infants and toddlers may constitute a viable screening tool for AS. In particular, assessment of communication characteristics, (e.g., speech and language development, interaction/communication and comprehension/understanding) as well as behavioral characteristics, (e.g., anxiety/energy levels, sensory issues, transitions, and fine/gross motor skills) are important areas to evaluate. Earlier screening tools could result in earlier diagnosis and the provision of needed appropriate services at a far earlier age than has typically been the case for children with Asperger Syndrome.

Keywords
Health Sciences, Speech Pathology, Psychology, Developmental, Speech Communication

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Aug 14, 2006

Date
DEDICATION

This research is dedicated to my wonderfully unique son and those individuals like him who challenge and broaden the narrow notion of "normal."
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The author wishes to give a heartfelt thank you to the families who participated in this research. Without your willingness to share your child and valuable time, this project would not have been possible.

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ABSTRACT

EARLY IDENTIFICATION OF CHILDREN WITH ASPERGER SYNDROME:

COMMUNICATION CHARACTERISTICS

by

Lynda D. Chouinard

University of New Hampshire, September 2006

Diagnosis of children within the Autism Spectrum Disorder (ASD) category varies significantly but children with Asperger Syndrome (AS) are typically diagnosed at a much older age than those with Autism (AD). The late childhood diagnosis of AS means a possible lapse in years that the child receives appropriate intervention and support. The purpose of this retrospective study was to gain further insight into what early communication and behavior characteristics can be identified in children from birth to three years who are later diagnosed with AS.

Parents of ten children with AS and under nineteen-years old were identified to participate in the study. The subjects’ parents answered The Rossetti Parent Questionnaire and participated in face-to-face, open-ended question interviews regarding their children from birth to age three. Parents were encouraged to share early memories about their child’s communication and behavior.
The results of this investigation indicate that evaluating behavioral and communication characteristics of infants and toddlers may constitute a viable screening tool for AS. In particular, assessment of communication characteristics, (e.g., speech and language development, interaction/communication and comprehension/understanding) as well as behavioral characteristics, (e.g., anxiety/energy levels, sensory issues, transitions, and fine/gross motor skills) are important areas to evaluate. Earlier screening tools could result in earlier diagnosis and the provision of needed appropriate services at a far earlier age than has typically been the case for children with Asperger Syndrome.
EARLY IDENTIFICATION OF CHILDREN WITH ASPERGER SYNDROME:
COMMUNICATION CHARACTERISTICS INTRODUCTION

Estimates of the prevalence of Autism Spectrum Disorders (ASD) in the United States vary considerably. Recently, two independent researchers reviewed published data on the topic and reported (the best conservative estimate of) the prevalence of ASDs in the United States is one child in 1,000 has an ASD (National Academy of Sciences, 2004). ASDs are a group of complex neurobiological disorders of development that exist throughout a person's life. The ASD category includes, Autistic disorder (AD), Asperger syndrome (AS), Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), (NICHD, 2005). Diagnosis of children within the ASD category varies significantly but typically a child with AD is diagnosed at the average age of three; whereas a child with AS is diagnosed at a much older age (NICHD, 2005). The late childhood diagnosis of AS means a possible lapse in years that a child receives appropriate intervention and support. Early indicators of AS could improve the diagnosis and consequent treatment for a child with AS.
This paper explores the possible existence of early indicators of Asperger’s Syndrome (AS) in children from birth to three. Existing research contains minimal information about the early identification of the syndrome in this population. Research does suggest that the onset of AS occurs later than autism and that AS is not typically recognized before the third year of life because of the normal development of language skills (Kline, 2004). The majority of research and clinical observations have been aimed at understanding autism or pervasive development disorders (PDDs) as a whole rather than specific syndromes. There is little direct data focused solely on AS. Research has been forced to extrapolate from work done on autistic disorder (AD), (Schultz, Romanski, & Tsatsanis, 2000). This creates significant gaps in our understanding of the development of children with AS and appropriate treatment protocols.

Nevertheless, the murky diagnostic criteria for the PDD’s is all that we currently have to work with. There is substantial overlap in the diagnostic criteria for AD and AS in the Diagnostic and Statistical Manual of Mental Disorders (DSM IV). This makes the diagnostic process muddy to navigate. AS was added to the DSM IV in 1994. The relatively new awareness of AS and the lack of diagnostic clarity and conciseness is partly responsible for the difficulty in diagnosing children in a timely manner. Kline (2000) adds that diagnostic issues are more complicated
in younger children with high-functioning social disabilities, such as High-functioning Autism and AS, than in older school age children.

Typically, AS presents for assessment rather late in development. The unique, subtle disabilities associated with AS tend to go unnoticed. This does not mean that symptoms are undetectable in preschool years. A comprehensive review of a child’s development at the time parents or educators express serious concerns, often reveals some early warning signals that antedated the referral (Kline, 2000). According to a study of 28 children by Gillberg et al., (1990), the symptoms most commonly observed were peculiarities of gaze, hearing, and play.
CHAPTER I

ASPERGER SYNDROME ON THE AUTISM SPECTRUM

AS is a neurodevelopmental disorder defined by marked difficulties in reciprocal social interaction, fluent but pragmatically impaired speech, and bizarre occupations and obsessions, (Szatmari et al., 2000). The DSM-IV description identifies the three core clusters of symptoms as “impairment of social interaction,” “restricted, repetitive, and stereotyped patterns of behavior,” and “clinically significant impairment in social, occupational, or other important areas of functioning.” These core symptom clusters are the same general features and characteristics exhibited by children clinically diagnosed with Autism - and who are described as having high functioning autism (Stoles, 2005).

According to the DSM-IV and International Classification of Diseases (ICD-10), the major differences that distinguish Autism Disorder (AD) from Asperger’s is that the latter is characterized by a lack of clinically significant language and cognitive delay (Szatmari et al., 2000). Two other areas of functioning, motor skills and visuospatial functioning, have
emerged as leading criteria for differentiating these two disorders. Research indicates both are significant areas of deficit seen much of the time in AS. More empirical research needs to be done to provide the rationale to evolve the current completely overlapping diagnostic criteria for AS and AD (Schultz et al., 2000). The vast majority of existing research has been conducted on children with the more severe types of PDDs, in particular - autism.

**Development in Children Birth to Three**

Typical developmental milestones in children from birth to age three are well researched and documented. Normal developing infants and toddlers exhibit predictable cognition, communication and motor patterns of growth. Children that fail to attain these behaviors or reach these developmental milestones are easier to identify and diagnose than those who may deviate more subtly or slightly from the norm. The early identification factors of AD are aspects of early childhood development that show a deviation or regression from the typical range of development. Early identification factors for the disorders on the AD spectrum, such as Asperger Syndrome, are less obvious and less understood.
The presumed similarities and differences in Autistic Spectrum Disorders can be described as being in a state of flux (Kutscher, 2005). “The problems can overlap, cause each other, occur simultaneously in different combinations and severities, change over time, and don’t even have one “official” group attempting the classification of the whole spectrum,” (p. 17).

- Asperger’s and autism share primarily the difficulty of recognizing the existence of others’ - trouble with theory of mind. Individuals with AS can speak; autism usually has limited speech.
- Children with Asperger’s appear less interested in forming bonds and have more trouble with “theory of mind” than Non-verbal Learning Disorder (NVLD) and Semantic-Pragmatic Disorder.
- “High Functioning Autism” is used by different authors to mean either Autistic Disorder with relatively spared speech and cognition; AS; or PDD-NOS (Kutscher, 2005, p.18).

**Early Identification Factors of Autism**

Many of the factors considered possible early identification features of autism are communication characteristics. A large body of research supports the need for these factors for early identification of autism. In a study by Gillberg et al., (1990), 21 out of the 28 infants who were initially
referred with possible autism were subsequently diagnosed. Two follow-ups were conducted by researchers at 6 months and 140 months in which all but one of the children had the autism diagnosis positively confirmed. Evidence suggests that a diagnosis of autism can be recognized in a child as young as 18 months old, however the mean age of diagnosis for typical autism is 5.5 years. For a child with AS, diagnosis can be as late as 11 years, in spite of much earlier parental worries (Connor, 2002; William et al., 2005; Howlin and Moore, 1997).

In a prospective, longitudinal study to identify indicators of Autism Spectrum Disorders (ASD) during the second year of life, Wetherby and Woods (2003) examined videotaped communication samples. The researchers found that nine observable behaviors were significantly different in the ASD group in comparison to the developmentally delayed (DD) and typically developing (TD) groups.

1) Lack of appropriate gaze
2) Lack of warm, joyful expressions with gaze
3) Lack of sharing enjoyment or interest
4) Lack of response to name
5) Lack of coordination of gaze, facial expression, gesture, and sound
6) Lack of showing
The findings are valuable towards the goal of early identification for children who fall within the autism spectrum. However, there is no information as to what percentage of the ASD population studied was diagnosed with Asperger syndrome.

According to the Autism Society of America (2005), the characteristic behaviors of autism spectrum disorders may or may not be apparent in infancy (18 to 24 months). It typically becomes clinically obvious during early childhood (24 months to 6 years). As part of a well-baby/well-child visit, (the) child’s doctor should do a “developmental screening” asking specific questions about (the) baby’s progress.

The National Institute of Child Health and Human Development (NICHD, 2005) lists five behaviors that signal further evaluation of the child is warranted:

- Does not babble or coo for 12 months
- Does not gesture (e.g. point, wave, or grasp) by 12 months
- Does not say single words by 16 months
• Does not say two-word phrases on his or her own by 24 months
• Has any loss of any language or social skill at any age

The NICHD states that these five symptoms indicate that the child should receive comprehensive evaluations by a multidisciplinary team knowledgeable about autism. The team may consist of a neurologist, psychologist, developmental pediatrician, speech-language pathologist, learning consultant, and other relevant professionals (NICHD, 2005, p. 4).

Research has indicated that differences between children with autism and non-autistic children can be detected at a very young age. Adrien, Lenoir, and Martineau, (1993) found that children with autism showed clear differences when compared to normally developing children during their first year of life. Deficits that were observed during the first year included the following:

• Limited social interaction
• Lack of smiling or of changes of facial expressions
• Hypotonia (decreased muscle tone)
• Poor attention
• An aversion to touch
Further impairments noted by Adrien et al. (1993) in children with autism during their second year of life included:

- Ignoring other people
- A preference for aloneness
- Lack of eye contact, gesture, & emotional expression
- Failure to show or point to an object
- Failure to orient to their name
- Abnormal orientation to visual stimuli (Connor, 2002)

Parents of autistic children noted that parents might recognize that their child (with autism) is different from others of a similar age but are unable to articulate these differences (Humphries, 2005). Difficulties in sorting out the individual personality differences and abilities of each child from the often subtle, vague symptoms of autism is a complex process. Further complicating matters is the possible sub-types of children with autism.

Children with autism can exhibit extremes in behavior and interests. Wing (1993) described two kinds of autistic infant, the placid, undemanding baby who rarely cries and the reverse, the screaming baby.
who is difficult to pacify. Other possible behaviors that may be present in either type are:

- Rocking and head banging
- Scratching or tapping at covers when in the stroller or crib
- Fascination with shiny, twinkling objects
- Lack of interest in people, animals, traffic, etc. (Humphries, 2005)

There are other signs that young children with autism may exhibit. Baird et al., (2005) in a recent clinical review referred to alerting signals of a possible autistic spectrum disorder (p. 490). During the first year, it is important to tap into concerns that the child’s parents may voice or imply. To identify red flags during the child’s second and third year, the researchers provide the following screening guideline:

1. Communication

Screening for impairment in language development comprehension is important. Any unusual use of language or poor response to name by the child is a warning sign. Other warning signs include a child that shows deficiency in non-verbal communication. Lack of pointing and difficulty following a point are suspect. A child who fails to smile socially, respond
to the smiling of others and share enjoyment exhibits compromised language development.

Baird et al state that the following signs are absolute indicators for referral:

- No babble, pointing, or other gesture by 12 months
- No single words by 18 months
- No two word spontaneous (non-echoed) phrases by 24 months
- Any loss of any language or social skills at any age

2. Social impairments

- Limitation in, or lack of imitation of, actions (for example, clapping)
- Lack of showing with toys or other objects
- Lack of interest in other children or odd approaches to other children
- Minimal recognition or responsiveness to other people's happiness or distress
- Limited variety of imaginative play or pretense, especially social imagination (that is, not joining with others in shared imaginary games)
- In his or her own world

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• Failure to initiate simple play with others or participate in early social games
• Preference for solitary play activities; odd relationships with adults (too friendly or ignores).

3. Impairment of interests, activities, and other behaviors

• Over-sensitivity to sound or touch
• Motor mannerisms such as biting, hitting, or aggression to peers;
• Oppositional to adults
• Over-liking for sameness or inability to cope with change, especially in unstructured setting
• Repetitive play with toys (for example, lining up objects); turning light switches on and off, regardless of scolding (Baird et al., 2005).

These markers outlined by Baird et al., encompass the diagnoses that fall within the Autism Spectrum Disorders, according to the definition provided by the DSM IV. Research determined that children with ASD in the second year of life can be distinguished from those with Developmental Delays (DD), (in which ASD was ruled out) and TD through systematic observation. Since AS is included in the definition of ASDs,
these findings are applicable to the early identification of children with Aspergers Syndrome.

Research Specific to AS

Research on Physical Characteristics in Diagnosis of Individuals

Limited research exists that specifically addresses the differentiating features of people diagnosed with AS. This body of knowledge largely focuses on the investigation of the differentiating physical, anatomical, or behavioral characteristics of those with Asperger Syndrome as compared to a normal population. Researchers have looked at physical factors that can be used to diagnose an individual with AS and further the understanding of the disorder.

Research has been conducted to examine possible differences in odor thresholds and identification in males with AS. Suzuki et al (2003) measured odor detection threshold and odor identification problems in 12 males with Asperger's syndrome and 12 matched control subjects to determine if there was a difference between the two groups. Odor detection thresholds were assessed by using a modified version of the two-bottle test of Cain et al., (1983). [When compared to the control group, odor detection thresholds were found to be unimpaired in the AS group however, odor identification was significantly impaired.] The
authors contend that these findings suggest that functional abnormalities of the orbitofrontal cortex may be associated with the social deficits of this autistic spectrum disorder (Suzuki et al., p. 107).

Other research has probed possible neurodevelopmental abnormalities underlying Asperger Syndrome. Gourion et al., reported a single case study of a 48-year-old male patient with AS who had Neonatal Tuberculous Meningitis (TBM). The observation of the AS patient, if confirmed, could support the hypothesis that the severe brain neonatal lesions caused by TBM may represent an epigenetic factor involved in the pathophysiology of the neurodevelopmental abnormalities underlying AS. According to this hypothesis, a previous study showed that TBM could induce later cognitive and motor neurodevelopmental disorders (Schoeman et al., 1997). There is a significant need for systematic research in this area, and neonatal somatic conditions should be systematically investigated in patients with Pervasive Developmental Disorders (Gourion, Pelissolo, Pelissolo, & Lepine, 2003).

Measurement of head circumference may be a viable diagnostic indicator of autism, AS, and ADHD. Gillberg and De Souza (2002) conducted a comparative study of the head circumference in autism, AS, and ADHD. All three groups had mean occipitofrontal circumferences (OFC) that were larger than the normal population at birth. When
measured again at 16 months, all groups had mean OFCs above the age and sex norms. The findings show significant difference in the AS group in that there is a high rate of two possible types of macrocephalus, one that is present at birth and the second that emerges a few years after development. Based on this study, the use of occipitofrontal circumference measurement in infants for early AS, AD, and ADHD identification may have diagnostic validity.

Another study has researched lower limb restlessness in AS using actometry. Actometry is a method for long-term recording of rest-activity rhythm and its disturbance caused by movement during the sleep cycle. A device with solid-state memory was worn on the wrist to save and add the signals. Tuisku et al., (2004) compared 10 adults with AS to 10 healthy controls, measuring their rest-activities by actometry. Results showed that the lower limb motor activity was significantly higher in the AS group. They also displayed a rhythmic, periodic movement pattern similar to akathisia. Akathisia is a feeling of restlessness associated with increased motor activity that may occur as a manifestation of nervous system drug toxicity or other conditions. These findings suggested a hypothesis of idiopathic akathisia and a special sensitivity to adverse effects of neuroleptic drugs (2002). Based on this study, higher than normal lower limb motor activity could be an early identification factor in children with AS.
Infants aged four to six months who were later diagnosed with autism exhibited a cluster of disturbances in movement patterns that were identifiable using the Eshkol-Wachman Movement Analysis (EWMN), (Teitelbaum et al., 1998). The EWMN is a generalized notation system used to record detailed very diverse movements on paper. In later work, Teitelbaum et al., hypothesized that these movement disturbances in infancy could be interpreted as “reflexes gone astray” (p. 11909). Among the children reviewed, some reflexes persisted too long in infancy, others first appear much later than they should. The asymmetrical tonic neck reflex is one reflex that does not appear when it should in a subgroup of autistic-to-be infants. The authors suggested that the asymmetrical tonic neck reflex could be used by pediatricians to quickly screen for autistic-to-be children, especially in families where there is a history of autism (Teitelbaum et al., 1998).

More recently, Teitelbaum et al., (2004) conducted a different study using Eshkol-Wachman movement notation. The results indicated that abnormal movement patterns can be detected in children with AS in infancy, independent of the presence of language. In preliminary results, the researchers proposed that a simple test using one such reflex, the tilting test, could be used for early detection of a subgroup of children with AS or autism. The tilting test takes 20-30 seconds and can be
performed by the pediatrician or parents. The lack of head verticalization response on even one side can serve as an early warning sign of neurological damage and indicate the need for additional testing for aberrant movement patterns. This study indicated that the tilt test could be used for early identification of children with AS.

**Research on Communication Characteristics**

Some research regarding the communication characteristics of people diagnosed with AS has been conducted, though this has mainly involved adolescents or adults. Whitely (2003) conducted a study on developmental, behavioral, and somatic factors in pervasive developmental disorders (PDD). The purpose was to identify any significant intragroup differences. The data obtained from this study showed that preliminary analysis of a selected number of behavioral and developmental diagnostic features of PDDs was able to differentiate AS from other PDD subgroups. Further analysis of selected somatic variables also suggested that patients with AS may present with a slightly different physiological presentation than other PDD subgroups (p. 10).

Clinical and empirical studies of children on the autistic spectrum have much in common with those of children with developmental language disorders, (Rapin & Dunn, 2003). However, the striking
difference in the language disorders of these two groups is that the ASD population has universally impaired pragmatics and comprehension of discourse. The authors contend that most adolescents and adults with AS or PPD-NOS that are highly intelligent “no longer manifest deficits in comprehension of discourse. What remains life-long are the semantic and pragmatic deficits such as difficulties in sustaining conversation, turn taking and allowing the conversational partner to introduce his or her topic, in prosody and direction of gaze (p. 171).”

Deficient auditory processing in children with AS was studied by Jansson-Verkasalo et al. (2002). The study examined 12 children with AS (four females, eight males, age range 7-12 years, mean 9.1) who met the criteria of the ICD-10. The control group chosen by a school psychologist, consisted of 12 healthy children matched by age and gender to the children with AS. Results suggested that “children with AS display abnormalities in auditory sensory processing, as indexed by the long-latency obligatory auditory event-related potentials (ERPs), (the P1 and N2 - peak amplitudes of an auditory wave complex) and by the index of preattentive sound discrimination, the mismatch negativity (MMN)” (p. 199). According to the authors this deficiency may account for or contribute to the perceptual problems encountered by children with AS.
These findings suggest that early indication of AS may include signs of auditory processing difficulties.

Three Asperger type autistic individuals were studied to explore the disordered recognition of facial identity and emotions. (Njiokiktjien et al., 2000). Thorough assessment methods were performed that included clinical and neuropsychological examinations, recognition of smells, photo screening tasks, and computerized tasks from the Amsterdam Neuropsychological Tasks battery. The three males were identified as B, C, and D and were 10 years 6 months, 6 years 7 months, and 8 years 3 months respectively. The author’s stated that B, and to a less severe degree C and D are AS type autistic boys with severe receptive and expressive emotional function disturbances in three areas of non-verbal social contact: face, body, and voice. They considered the absence of emotion perception as a crucial pathogenetic factor for the autistic behavior and this clinical picture seems to be rooted in a brain right hemisphere or bilateral deficit. All three males had poor age and gender identification and partial prosopagnosia, a facial processing disorder that is not necessarily present in all autists with facial emotion perception problems. Mental rigidity, poor visual mental imagery and imagery of other people’s perspective as well as pragmatic language aspects contribute to absent social relatedness as well, while the dysphasic
symptoms as well as most motor symptoms are a specific co-morbidity. Ritualism and bizarre or narrow interests are possibly more a consequence than a cause of absent social relatedness and might be related to other problems in autistic children (Njioiktjien et al., p. 89).

Co-morbid Psychiatric Issues

Many years usually elapse before a child is properly diagnosed with AS, years that can be frightening, frustrating, stressful, and even agonizing for the child and family. Wing (1981) reported that parents, in their child’s early years, are usually confused and distressed by their children’s strange behaviors. The worries for their child are often overwhelming and the answers very slow in coming. For many parents, putting their pre-diagnosed AS child on the school bus each morning is akin to sending their unarmed offspring into a fierce battle. Alone, misunderstood and trying to make sense of a world that he perceives very differently than most, the daily challenges can create substantial emotional problems. The longer a child goes undiagnosed the more likely that his needs go unmet and co-morbid conditions may develop or compound.

Research conducted by Howlin and Moore (1997) emphasized how diagnoses of autism were typically made after the child turned four, even though almost all of the parents identified significant concerns during their
child’s first two or three years. There are confounding and often accompanying diagnoses of depression and/or Attention Deficit Hyperactivity Disorder (ADHD), which contributes additional challenges to the diagnostic procedure (Dahle and Gargiulo, 2005). Clinically diagnosable anxiety and varying degrees of depression may be found in individuals with AS, especially in late adolescence or early adult life (Wing, 1981). The longer a child goes without diagnosis and proper developmental support, the greater the risks for co-morbid psychological issues.

Co-morbid psychiatric issues are seen in many childhood disorders. In a discussion of Non-verbal Learning Disability (NLD), which shares many of the AS factors and recommended treatment methods, Franz (2000) noted that these students struggle on multiple levels. As in AS, academic, cognitive, communication, and social skills are all impacted to some degree. The social isolation and withdrawal that these children may need to deal with can lead to higher incidence of depression, anxiety, and frustration. The child may become more rigid and less responsive to intervention attempts. Franz noted that early intervention is therefore critical before the secondary issues of psychological maladjustment develop.
Gadow, DeVincent, Pomeroy, and Allen (2004) conducted a study to describe and compare psychiatric symptoms in preschool children with PDD. Findings showed that significant DSM-IV psychiatric symptoms are frequently present in preschoolers with PDD who are referred for psychiatric evaluations. Comparisons within the study indicated that DSM-IV psychiatric symptoms are more severe for the PDD population than children in regular and special early childhood programs, and to some extent nonPDD psychiatric referrals. Methodology included parents and teachers completing a DSM-IV-referenced rating scale called the early child inventory-4 (ECI-4). The PDD group was rated by parents more so than teachers to have more severe anxiety and depression symptoms. "The Asperger group was rated by both groups of informants as more oppositional than the autism and PDDNOS subgroups" (Gadow et al., p. 379).

Co-morbidity can further complicate the diagnostic picture, as autism and PDD can coexist with hyperkinetic and attentional disorders, obsessive-compulsive disorder, and developmental disorders of motor function, as well as specific and general learning problems, (Baird et al., 2005). Researchers contend that early diagnosis and carefully targeted intervention have the potential to positively affect outcomes, particularly
in the management of behavior, functional skills, and communication problems.

**Benefits of Early Intervention**

There is increasing evidence that early intervention may be a critical element underlying the success of intervention programs for children with AS, (Connor, 2002). Connor states that access as soon as practical to a **structured** approach, with communication skills as a prime target, is desirable whatever the underlying orientation of the program. Since the typical child with AS is not accurately diagnosed until the later school years, much critical intervention time is lost. A person who is diagnosed with AS at age ten or sixteen or twenty-five or even forty-five will have different therapy and treatment needs from a child diagnosed at two or at five, (Sicile-Kira, 2004). For example, a toddler may need intensive early interventions to learn to speak or develop a system of communication. An older child may have language skills but no social skills. Adults may have sensory processing issues that could be helped through physiologically oriented therapies (p. 88).

Empirical research is compiling evidence of the effectiveness of intensive early intervention for a substantial proportion of children with autism spectrum disorders (ASD), (Wetherby & Woods, 2003). Successful
interventions use a range of behavioral and naturalistic approaches. These have a much greater impact when provided before age 3½ than after age five (p. 1). They contended that this underscores the importance of improving early identification, noting that there are still no biological markers therefore screening and diagnosis must be based on behavioral features.

Speech and Language therapy is one of the key providers of early intervention services to children ages birth to three as mandated by Part C of the Individuals with Disabilities Education Act (IDEA) first instituted in 1986 (Lipinski et al., 2001). According to the American Speech-Language-Hearing Association (ASHA), “speech-language pathologists and audiologists provide more than half of all services under the IDEA program. Communication skills, language and literacy abilities define the very core of learning and set the course for school success,” (ASHA, 2006).

A California Department of Developmental Services (2003) publication outlines best practice guidelines for the screening, diagnosis and assessment of ASDs. The authors contend that early identification leads to better outcomes. In addition, recent studies have demonstrated that early therapeutic intervention is associated with the best developmental, behavioral, and adaptive outcomes. Since ASD-specific
early intervention services are dependent upon early detection and formal diagnosis, timely screening for ASD, at-risk identification, and prompt referral for comprehensive evaluations and assessment are paramount (p. 9).

**Rationale for Further Research**

There is significant evidence to suggest the existence of a hereditary subgroup in autism (Gillberg, et al., 1992). However, researchers clarified that the data about the character of the genetic predisposition and range of Autism Spectrum Disorders that can be explained by genetics is not substantial enough to provide credible answers. In studies by Gillberg et al., the autism subgroup in which the sole etiology can be attributed to pure genetics can range from 6% to 63%, leaving many unanswered questions.

The phenotypic overlap between AS and AD is substantial, making it likely that many of the fundamental mechanisms will also be similar for the two conditions, (Schultz et al., 2000). Researchers also contended that there is lots of work that needs to be done at the phenotypic level to sort through the levels of classification for AD and AS. It is critical to understand the neurological systems that normally mediate social functions and regulate repetitive behaviors and patterns of interest.
Recent reliable data are emerging on the role of the amygdala and the relationship between the amygdala and particular systems in the temporal and frontal cortices. Limbic system abnormalities are hypothesized to cause early affective impairments that lead to social deficits and problems with repetitive behaviors. In summary, Schultz et al (2000) propose that amygdala-frontal and amygdala-temporal systems serve key roles in the development of AS and AD (p. 4-5). Considering the possible phenotype relationship between AS and AD, it is reasonable to suggest that the early identification factors in children from birth to three years of age could share similarities.

The Center for Disease Control (CDC) spearheaded a campaign to make doctors and parents aware of signs and symptoms for early detection of autism and autism-related disorders (Yee, 2005). Posters and checklists outline normal development expectations and can serve to alert parents and professionals of the need to refer a child to a specialist. According to Yee and the CDC, early detection of autism is a pressing issue because more children than ever before fall into the category of autism or autism-related disorders. Rice (2005), a behavioral scientist with the federal health agency said that if a child has a developmental concern, it is important for families and providers to seek early intervention because it can really have a positive impact. Rice notes that early
intervention does not necessarily cure or ameliorate the issue, but it can help the child to a higher level of learning and living.

Further research is needed to expand the current understanding of early signs for diagnosis of children with autism to include and differentiate early signs for children with Aspergers. This knowledge could be used to provide guidelines for parents and professionals to identify children that need further evaluation. There may be striking similarities between the behaviors and personalities of children with AD and those with AS beginning at a very young age. The symptoms that a child with AS may exhibit may be insidious and subtler making them even more difficult to pinpoint than the child with autism. The discovery of common behavioral, social, and cognitive factors among infants and toddlers that are later diagnosed with AS, would be a welcome addition to existing knowledge. This information could help diagnose children that otherwise would not be diagnosed until years later. Early intervention could be initiated and there could be reduced development of future co-morbid psychological factors.

Since the vast majority of early identification factors for AD reflect communication characteristics in young children, it is reasonable to expect that this may also be the case for children with AS. Little
information exists that specifically focused on communication characteristics of early identification factors for children with AS. There is a significant lack of knowledge about the early childhood years from birth to age three of children who are later diagnosed with AS. Information from clinical observation or data collected from research would further the understanding of the early years of these children and perhaps contribute to the early identification of AS.
Chapter II

PROCEDURES

Purpose

The purpose of this retrospective study was to gain further insight into what early communication characteristics can be identified in children from birth to three years who are later diagnosed with Asperger Syndrome (AS). Information gathered will further the understanding of the early years of these children and help us recognize observable characteristics or behaviors that may exist in this population. This understanding may contribute to the early identification and treatment of children with AS.

Specific research objectives were:

- Identify/verify previously reported common communication and behavioral traits in very young children with AS.
- Identify any unique characteristics observed by parents of very young children with AS as compared to typical children.
• Collect data from parents of AS children concerning perceived strengths and weaknesses of their child exhibited from birth to three years of age.

• Observe behavioral traits and characteristics with respect to communication skills of very young children who are later diagnosed with AS.

**Methods**

Subjects were identified via personal contacts rather than through a random pool of subjects. This procedure was elected because the researcher believed subjects would be more willing to participate if there was a person-to-person referral. Furthermore, the researcher hoped that the quality of participation would result in successful completion of the study. Subjects were selected in a variety of ways, as summarized in Table 1, *(Subject Selection).*
Table 1

Details of subject selection indicating the number of families initially referred by each referral source, the number of families who participated, and the number of child subjects involved.

<table>
<thead>
<tr>
<th>Referral Source</th>
<th>Subjects Identified</th>
<th>Participating Families</th>
<th>Number of Child Subjects</th>
</tr>
</thead>
<tbody>
<tr>
<td>27 Graduate students-UNH, CSD</td>
<td>Four families</td>
<td>Three</td>
<td>Three</td>
</tr>
<tr>
<td>7 Graduate students-UNH, OT</td>
<td>One family</td>
<td>One</td>
<td>One</td>
</tr>
<tr>
<td>7 Faculty Members-UNH, Dept CSD</td>
<td>Four families</td>
<td>Two</td>
<td>One</td>
</tr>
<tr>
<td>2 NH Psychologists</td>
<td>Two families</td>
<td>One</td>
<td>One</td>
</tr>
<tr>
<td>4 Friends living in Southern, NH</td>
<td>One family</td>
<td>One</td>
<td>One</td>
</tr>
<tr>
<td>2 Employees at Easter Seals NH</td>
<td>Two families</td>
<td>Two</td>
<td>Three</td>
</tr>
</tbody>
</table>

A total of 34 current graduate students enrolled in the Communication Sciences and Disorders or Occupational Therapy programs at the University of New Hampshire, were identified and asked to provide possible connections to families with children, (currently eighteen years old or younger) diagnosed with Asperger’s syndrome. Students and professionals in both disciplines (Speech-Language Pathologists & Occupational Therapists) are likely to work in environments (e.g., school districts, early intervention programs) that serve children with AS. Recommendations from fellow graduate students helped identify five families. Of the five families, three participated in the study. These names were then supplemented by soliciting recommendations from seven faculty members of the Department of Communication Sciences and
Disorders at the University of New Hampshire. Discussions with the faculty netted four possible families. One of the recommended families was previously identified by a graduate student. Of these four nominated families, two participated in the study.

Two practicing New Hampshire psychologists who specialize in treating children with disabilities were asked to provide possible connections to families with children diagnosed with AS. The first was recommended by a participating parent, who a doctorate in psychology, and has been certified by the American Board of Professional Psychology (ABPP) for professional achievement. Two families were identified and one of the two participated in the study. The second is a Neuropsychologist who co-founded a New Hampshire neurodevelopment center and specializes in assessing and interpreting tests related to functions of the brain. The second psychologist may or may not have attempted to contact eligible families. No families contacted researchers in connection with the second psychologist.

Several other sources were approached to provide recommendations for participants in the research. Four personal friends of the researcher living in Southern New Hampshire were asked to provide possible connections to families with children diagnosed with AS. These
four friends each have a Bachelor degree, families, and work and socialize in four very different environments, thereby having potential connections with families of children with AS. One family was identified and participated in the study. Due to an association with the Autism Diagnostic and Treatment Network, two employees at Easter Seals New Hampshire were asked to provide contacts. Two families were recommended for the project and participated in the research netting a total of three subjects, all children below the age of eighteen and diagnosed with AS. Inquiries were also made to several New Hampshire schools that offer programs specifically for children with Autism Spectrum Disorders to provide possible connections with families of children diagnosed with AS. One school did not respond to the researcher’s requests. A representative from the second school did agree to receive information and pass it on to prospective families. No families contacted researchers in connection with the second school.

Confidentiality of the participating families and children was maintained throughout the study by the use of a coding system. Identifying information of the participants and subjects was inaccessible to anyone but the researcher. During the interviews, pseudonyms were utilized for note taking as well as the type written transcripts of the digitally recorded interviews.
Parents and others were told that the purpose of the study was to identify early communication characteristics of children who are later diagnosed with Asperger Syndrome. The study was described and explained to parents and others as a retrospective research project that relies on the reporting of parents about their children between birth to three.

Several measures were taken to ensure valid reporting by subjects. Parents were asked to "do their best" in answering the Rossetti Parent Questionnaire "for when their child was between ages birth to three" and answer only what they could remember. Any inconsistency between the questionnaire responses and the information collected during the interview were noted by the researcher. Parents were either asked to clarify the inconsistency during the face-to-face discussion or later contacted via email or telephone and requested to clarify the inconsistency.

Subject Description

The ten subjects are male children age eighteen or younger who are diagnosed with Asperger syndrome. There was no intention to identify only male subjects but this was the unanticipated result of the personal referral selection process. The mean age of subjects was 12.8 and the
median age was 13.5. The grade level for the children at the time of the study ranged from first to twelfth grade. The mean grade level was 7.4 and the median grade level was 8.5. Three out of the ten subjects [1, 4, 5] are the only child in the family. Seven of the subjects [2, 3, 6, 7, 8, 9, 10] have one or more related siblings. The reported age at the time of diagnosis ranged from three to thirteen for nine of the ten children (unknown for one subject). The mean age for diagnosis was 7.33 and the median age was seven.

The nine participants are parents of a child (or children) diagnosed with Asperger syndrome. The nine families recommended and selected reside in northeastern New England. At the time research was conducted eight families lived in the state of New Hampshire and one lived in the state of Maine. The annual household income for the families was as summarized in Table 2 (Annual Household Income) and the reported education level of participating parents was as reported in Table 3 (Parent Education Level).
Table 2

Annual household income as reported by the nine participating parents of the subjects.

<table>
<thead>
<tr>
<th>Household Income</th>
<th>Number of families within the range*</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-20,000</td>
<td>One</td>
</tr>
<tr>
<td>20,000-50,000</td>
<td>Three</td>
</tr>
<tr>
<td>50,000-80,000</td>
<td>Two</td>
</tr>
<tr>
<td>80,000-100,000</td>
<td>One</td>
</tr>
<tr>
<td>Over 100,000</td>
<td>Two</td>
</tr>
</tbody>
</table>

*No reported household income for two of the families

Table 3

Level of education of participating parents as reported by the families. Six of the families reported for one parent while two reported for both mother and father's education.

<table>
<thead>
<tr>
<th>Level of Education</th>
<th>Number of parents at the level</th>
</tr>
</thead>
<tbody>
<tr>
<td>High school</td>
<td>Three</td>
</tr>
<tr>
<td>Some college</td>
<td>One</td>
</tr>
<tr>
<td>Two-year college</td>
<td>Three</td>
</tr>
<tr>
<td>Four-year college</td>
<td>One</td>
</tr>
<tr>
<td>Master Degree</td>
<td>Two</td>
</tr>
<tr>
<td>Doctorate Degree</td>
<td></td>
</tr>
</tbody>
</table>

*No reported education for one of the participating families.

**Procedures**

Families that agreed to participate in the study were contacted via email or telephone and asked to provide their mailing address. The *Study Introduction Letter, Informed Consent Document, and The Rossetti Infant-Toddler Language Scale (RITLS) Parent Questionnaire* along with a pre-addressed, postage paid envelope were mailed to families. Parents were
requested to fill-out and sign the *Informed Consent Document* and answer the *Rossetti Parent Questionnaire*. Once completed, parents could either mail the paperwork back to the researcher or bring it in person to the interview meeting. Arrangements were made via email or telephone for a face-to-face meeting with each of the nine parents.

The RITLS is a criterion-reference measure compiled from behaviors recognized and used by leading authorities in the field of infant and toddler assessment. Since RITLS is a criterion-referenced tool there are no norms provided. Each child’s performance is compared to known developmental parameters and categorized as a mild, moderate or severe delay. In particular, Speech-Language Pathologists use this procedure for examining language development in children between birth to three years. The RITLS was designed to provide the clinician with a comprehensive, easy-to-administer, and relevant tool to assess the preverbal and verbal aspects of communication and interaction in the young child. The RITLS assesses the preverbal and verbal areas of: Interaction-Attachment, Pragmatics, Gesture, Play, Language Comprehension, and Language Expression (Linguisystems, 2005).

The *Rossetti Parent Questionnaire* form is part of the evaluation used to gather information via parent reporting of the child’s behavior.
Questions for parents are aimed at gathering information about the child in the following areas: Interactions and Communication Development, Comprehension and Understanding, and Speech and Language Development. There are a total of thirty-six questions, which request a multi-word descriptive response. Twenty-one of these questions ask for a yes or no response and request a follow-up explanation for that response. The researcher believed that this type of parent questionnaire format could potentially generate more information than a checklist format, therefore providing more data for gathering additional information during face-to-face interviews. This type of open-question format also provided more time for the parent to think about the responses they were giving and then support those responses with specific details about their children thereby improving reliability of their responses. Opportunity to further describe and clarify their Rossetti Questionnaire responses arose during the interviews, serving to further validate the parent reporting.

There are several compelling reasons for choosing the Rossetti to use in this study. First, the Rossetti Infant-Toddler Scale has been used in previous research projects (Nott, Cowan, Brown, Wigglesworth, 2003; Zeit, 2001) as a tool for measuring infant-toddler language development. Second, the Rossetti is suggested as a tool for assessing early communication in ASD (Paul, 2004) and as a test for autism (Autism Index,
Third, this communication assessment program was regarded as a respected professional tool and was readily available in the researcher’s on-campus speech-language hearing clinic.

For the purposes of this study, the Rossetti Parent Questionnaire was utilized in a non-standardized manner. Parents were requested to answer the questions retrospectively and respond to the questions thinking back to when their child was between the ages of birth to three. The Rossetti Parent Questionnaire was specifically used for gathering information on early communication characteristics of the child subjects. No standardized application of the RITLS was utilized for this research.

Parents were invited to share materials with the researcher (e.g., video tapes, baby books, journals, and reports) that documented communication skills of their child from birth to three. This aspect of the study was included in the design to ensure there was adequate data/material for the researcher to examine qualitatively. However, only one parent (Subject 2) out of the nine families opted to provide examples of reports and artwork. The remaining eight did not supply any materials for review. Due to the lack of participation in this aspect of the study and the abundance of written and verbally reported information, the researcher disregarded the materials on child subject # 2 and did not
utilize any of the information in reporting results of the research. The parent responses to the Rossetti Parent Questionnaire, interview discussions, email correspondences, and subsequent phone conversations generated ample data/material for the purposes of the research objectives.

The interview process was used to collect data for the study because the researcher believed this method best supported the qualitative research objectives. In-depth information can be pursued around the topic to provide the story behind the participants' experiences (McNamara, 1999). The *general interview guide approach* was utilized to ensure that the conversation was focused yet still flexible to gather the same general areas of information from each participant (Valenzuela & Shrivastava, 2002).

The interview meeting was held either in the family's home or a mutually agreed upon location. The discussions were scheduled for a minimum of one-hour. The range of the recorded interviews was 1:04:50 to 1:38:50 hours. The mean of the recorded interviews was 1:08:22 hours. With parent permission, each meeting was recorded using the OLYMPUS Digital Voice Recorder model WS-100. At the interview, parents were asked open-ended questions about their child/children based on the
responses they gave to the *Rossetti Parent Questionnaire*. The purpose of the interview was to collect narrative information from parents about their children’s early childhood characteristics, behaviors, and experiences. Open-ended questions put forth by the researcher were non-scripted (no prepared questionnaire was used) and non-biased (not designed to influence in a particular direction), and based on information generated by the parent questionnaire or during conversation with the parent. During the interview, the researcher took notes of parent responses on the *Rossetti* and on additional notebook paper as needed. Parent and child anonymity was maintained during the written recording of data through use of pseudonyms.

For reliability purposes, digital recordings were transcribed by the researcher and compared to notes taken by the researcher during the interviews. Five-minute segments from each of the nine interview sessions were randomly selected using the [www.randomizer.org](http://www.randomizer.org) system. Each interview was divided into eight to eighteen, five-minute sections depending on the length of the recording. The number of five-minute sections from each session was then entered into the automated randomizer. Using this method, a random number was generated for each of the nine sessions. The nine corresponding five-minute interview
segments were then recorded onto two compact discs. The recorded discs were distributed to the outside raters and reviewed for reliability.

Two second year graduate students with a Bachelor of Science in Communication Sciences and Disorders provided inter-rater reliability for the interview process. The two graduate students were asked to agree or disagree with the researcher’s transcription of the digitally recorded interviews. A hard copy of the interview discussions was mailed to each student along with a CD of the randomly selected five-minute segments. The outside raters were asked to listen to each of the nine recorded segments, then locate and mark the corresponding section of text on the interview hard copy. If the rater felt the intent (not necessarily the wording) of the parent’s response did not match the text portion, they were requested to write specific notes as to what they disagreed with and explain why. Parent and child anonymity was maintained with use of pseudonyms.

To further examine reliability and validity of results based on the Rossetti Parent Questionnaire, a third graduate student agreed to be an outside rater. Two of the ten child subjects were randomly selected using the www.randomorganizer.org system. The documented Rossetti parent responses were reviewed and interpreted by the third rater. The rater’s
interpretation was then compared to the researcher's to check for reliability.

Concerns to internal and external validity have been considered for both the study design and interpretation of the data collected. This retrospective study relies on parent reporting based on memory of when their child was between the ages birth to three. Reporting based on memory is not as accurate as direct observation and recall ability will vary between parents. The older the child is now, the less accurate or more biased the parent reporting may be. Furthermore, parents may have interpreted the Rossetti questions differently from one another and misunderstood the intent of the questions.

Potential misinterpretation and bias of the researcher was a concern for internal validity. Although the researcher had the best interests of the children and families in mind, personal feelings and impressions are insidious to qualitative analysis. The original study design included the use of two student outside raters but an additional student outside rater was recruited to provide a more rigorous test of reliability. The findings of the three outside raters supported the researcher's interpretations for both the interviews and Rossetti Parent Questionnaire with one-hundred percent agreement.
CHAPTER III

RESULTS

The purpose of this study was to research the communication characteristics of children ages birth to three who are later diagnosed with AS. Four objectives were designed to generate data to identify possible common communication characteristics within the study population.

The first objective was to identify/verify previously reported common communication and behavioral traits in very young children with AS. The second objective was to identify any unique characteristics observed by parents of very young children with Asperger Syndrome as compared to typical children. The third objective was to collect data from parents of AS children concerning perceived strengths and weaknesses their child exhibited from birth to three years of age. The final objective was to observe behavioral traits and characteristics with respect to communication skills of very young children who are later diagnosed with AS.
Responses from the Rossetti Parent Questionnaire and interviews with the nine parents generated the results listed below. The Rossetti questions are numbered in the same order as the questionnaire format. The interview follow-up questions are designated by an "F" along with a second letter if more than one question was asked in that section.

The Rossetti
INFANT-TODDLER LANGUAGE SCALE
And Follow-up Interview Questions

Interaction and Communication Development

Do any of the following describe your child as an infant or toddler?

If you circle "yes" for any of the following questions, please use the space provided to explain.

1. Was your child ever separated from you for a long time?

Nine of the ten children (90%) were reported as never being separated for a long period from their parents. The one child (10%) that was separated for a long time [was due to adoption.]
F. Home—did he prefer to be home?

Four of the ten children (40%) preferred to be at home. One of the four parents noted that their child was okay “doing errands” and another parent noted that “he does travel pretty well.”

2. Did your child require frequent hospitalization?

One hundred percent of the parents reported that their child did not require frequent hospitalization.

F.a) How was his overall health?  F.b) Did he complain of headaches or belly aches?

Four of the ten children (40%) were reported as having “good” or “pretty good” overall health. All of the parents related some type of health issue with their child. These data are summarized in Table 4 (Subjects’ Health Issues).
Table 4

Description of the subjects' health issues as reported by parents during the interview portion of the study.

<table>
<thead>
<tr>
<th>Subjects</th>
<th>Health Issue</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td>Seasonal allergies/congestion &amp; gastric distress at times, some headaches</td>
</tr>
<tr>
<td>#2</td>
<td>Dehydrates easily (hospitalized once) &amp; frequent nosebleeds</td>
</tr>
<tr>
<td>#3</td>
<td>Frequent ear infections, adenoids removed, bowel obstruction, diminished pain awareness, over weight</td>
</tr>
<tr>
<td>#4</td>
<td>Sinusitis/allergies, only 3 ear infections, some stomach aches, only 3 headaches, endurance problems-fatigues easily</td>
</tr>
<tr>
<td>#5</td>
<td>Low body weight; high anxiety decreases appetite.</td>
</tr>
<tr>
<td>#6</td>
<td>Stocky as young child but got very skinny, hates to be cold, frequent headaches</td>
</tr>
<tr>
<td>#7</td>
<td>Chronic ear infections-tubes cleared, fast metabolism-very thin</td>
</tr>
<tr>
<td>#8</td>
<td>Frequent ear infections, roseola twice &amp; chicken pox twice</td>
</tr>
<tr>
<td>#9</td>
<td>Always sweaty, sees better out of large part of eye, chicken pox twice</td>
</tr>
<tr>
<td>#10</td>
<td>Diagnosed with asthma when very young, had frequent ear infections</td>
</tr>
</tbody>
</table>

3. Did your child resist cuddling?

Three out of the ten children (30%) were reported by parents to have resisted cuddling.

F.a) Did he ever exhibit “touch” sensitivity or show an aversion to being hugged, touched, etc?

Four of the ten children (40%) showed an aversion to touch while four out of the ten (40%) liked “deep pressure” or were always seeking sensory input. One of the ten children (10%) was not in either group but had aversion to brushing his teeth, toenails &
fingernail clipping. The same child never reported being “hot, cold, hungry” so may have reduced sensory awareness.

F.b) Was he particular about clothing as a toddler?
Eight out of the ten children (80%) were reported as being particular about clothing with two parents noting that “he liked clothing loose” and six parents noting that the “feel” of fabric or seams was an issue.

4. Was your child often difficult to calm?
F.a) If yes, explain what you mean by this.
Seven out of the ten children (70%) were reported by parents as often being difficult to calm. Frustration levels were reported as high for all seven of these children.

F.b) Did he have any fears or strong dislikes?
Seven out of the ten children (70%) were reported as having strong fears or dislikes.

5. Was your child often colicky?
Three out of the ten children (30%) were reported as being often colicky.
F.) What is bedtime & sleep like for your child?

Six out of the ten children (60%) had “difficulty settling down” to go to sleep and three (30%) additional children received “calming” input prior to going to sleep or had “ritualistic behaviors” though they were not described as having difficulty settling down by parents.

Five out of the ten children (50%) have a history of night terrors. Two of these children had “very bad” episodes for “quite a while,” but one only had them “once or twice.”

Two out of the 10 children (20%) “did not sleep much” according to their parents. Only one (10%) child was reported as having no bedtime or sleep issues.

6. Did your child seem very restless?

Four out of the 10 children (40%) seemed very restless according to their parents.
F.a) Describe his ability to attend/focus on an activity.
Five out of the ten children (50%) were reported by their parents as being "intensely focused on an activity that interested him" and can concentrate to the exclusion of things going on around him.

F.b) What were transitions between activities like for him?
Nine out of the ten children (90%) had difficulty with transitions between activities with parents using the following descriptive language: "tough, challenging, difficult, hard, did poorly, a mosquito has a better attention span."

7. Did your child seem very inactive?
Only one out of the ten children (10%) was reported as being "inactive" while the other nine (90%) were reported as being "active."

F.a) How were his fine motor skills?
Eight out of the ten children (80%) had "poor" fine motor skills according to parent report.

F.b) How were his gross motor skills?
Three of the ten children (30%) had “great” gross motor skills according to parent report.

Three of the ten children (30%) had “okay” gross motor skills according to parent report.

Four of the ten children (40%) had “poor” gross motor skills according to parent report.

F.c) What was his energy level like from birth to three?
Eight out of the ten children (80%) were described as having “high energy” levels and the remaining two children (20%) were described as having “average energy” levels.

8. Was your child non-responsive when you “talked” with him/her?
Three out of the ten children (30%) were described by their parents by being “non-responsive” at times.

F. Who was your child most closely attached to from ages birth to three?
All ten of the children (100%) were most closely attached to their mother.
9. Did your child often avoid eye contact with you or others?

Five out of the ten children (50%) avoided eye contact with their parents or others.

10. Did your child often play with toys in an unusual manner?

Seven out of the ten children (70%) were reported by their parents as having played with toys in an unusual manner. Three (30%) of the remaining parents answered "no" but described scenarios which could be interpreted as "unusual."

F.a) Give me some examples of how he played with toys.

The parent of Subject #1 responded "no," but gave the following example of play with play-doh: "...using tiny pieces to play war at age two."

The parent of Subject #2 responded "no," but described obsessions and interests that changed with fads and added that he keeps "collections of things."

The parent of Subject #3 responded "no," but explained that her son was overly focused on villains and "things of a dark nature" and collected (many) action characters.
The parent of Subject #4 reported that he, “Lined things up, red to red, yellow to yellow; always played the same way (e.g., with figurines); only used red Leggo’s and lined (them) up.”

The parent of Subject #5 reported that he was fascinated with shampoo bottles, lemons and (mechanical) agitators.

The parent of Subject #6 reported that he lined-up cars and rode a child-sized motorized vehicle around and around in circles.

The parent of Subject #7 reported that he repeatedly lined-up trains.

The parent of Subject #8 reported that he lined-up trains along room heaters and, also lined-up Power Rangers and Ninja Turtle figurines.

The parent of Subject #9 reported that he lined-up trucks, cars and trains all around the house.
The parent of Subject #10 reported that he was fascinated with cars, arranged them in specific patterns and designs and was able to identify all the makes and models.

F.b) Any special attachments to a toy/s?

Eight out of the ten children (80%) had an attachment to either a blanket or favorite stuffed animal.

F.c) Did he prefer or favor a particular color?

Three out of the ten children (30%) preferred the color red while one child (10%) had an aversion to “red.”

11. Did your child use gestures to communicate?

Five out of the ten children (50%) were reported by parents to use gestures to communicate.

F. Did he ever exhibit hand flapping or other physical behaviors?

Four out of the ten children (40%) were reported to exhibit hand or finger flapping between ages birth to three.

12. Did your child show interest in the people and things around him/her? If you answer “no” to this question, please explain.
Seven out of the ten children (70%) were reported to show interest in the people and things around them. The remaining three children (30%) “would not join other kids in play.” Several parents commented, “he often seemed lost in his own world’’ and “only interested in his activity at the moment; he acted deaf.”

F.a) How was your child with strangers?
No particular problems with strangers were reported for nine out of the ten children (90%). One child (10%) avoided eye contact with strangers and was very uncomfortable upon meeting someone he did not know.

F.b) Family time-Any behaviors when younger (birth to three) that were disruptive during family time?
Subject # 1, “Hated being told no.”

Subject # 2, “Did not understand personal body space.”

The parent of Subject # 3 reported, “The extended family (on father’s side) has always said he was different and are not sure what to think or do with him.”
Subject #4 was "Difficult to calm and would throw tantrums that lasted for hours...Had rituals to follow for meals, bedtime and other certain activities or else he would have a tantrum."

Subject #5, "Had some inappropriate behaviors; hair grabbing, yelling, need to move, personal space (in school setting)."

Subject #6 was described by his parents as, "Difficult to calm when he becomes upset...If he was going some place [exclusively focused on something], no one else was there...Needs his space but is not aware of anyone else's body space."

Subject #7 exhibited high anxiety and his issues caused stress in the parents' relationship.

The parent of Subject #8 reported, "He doesn't like it if there's too much going on around him, he gets over stimulated. As an infant he preferred to be off by himself...severe sensory issues...just putting him in the water [bath] made him scream." These issues caused stress in the parents' relationship.
The parent of Subject #9 reported, "He did not laugh for the first time until he was two...you know, when they’re little and you kiss their feet to make them smile...he was stiff." These issues caused stress in the parents' relationship with one another.

The parent of Subject #10 reported, "[He had] temper tantrums and would have an immediate reaction and start to cry... [He would] make some sound...might be a made up word and he would do it over and over again..." These behaviors were disruptive during family time.

Comprehension and Understanding

*When you compare your child to other children of the same age.*

13. Is your child easily confused when there are many things taking place around him/ her? *If you answer “yes” to this question, please explain.*

F.a) What happened when there were a lot of things going on around him?

Nine out of the ten children (90%) were reported by parents as being easily confused when there were many things taking place around them. It should be noted that the parent reporting “no” related several examples during the interview that intimated a “yes”
response. Parents described the following situations or behaviors in which their child exhibited confusion.

Subject #1 - Certain noisy environments such as the food court at the mall overwhelm him.

Subject #2 - At times he will "zone out" or withdraw and will need to be addressed individually in order to regain his attention.

Subject #3 - Cheeks bright red when anxious.

Subject #4 - Takes him a bit to focus and process if a lot is going on around him. Very fidgety and hyper (active) as a young child; restless; picked nails and pulled things. Put his hands down his pants touching his thing (penis) thirty-plus times a minute; he had a lot of tics."

Subject #5 - The parent reported that understanding personal space is an issue and that he would get "too close to someone, (be) in their face." He exhibited inappropriate behaviors such as "hair grabbing; yelling when not heard in a regular voice." Sounds
are especially problematic when many things are taking place around Subject #5.

Subject #6 - “He would get irritated; did not like loud noises. Red cheeks and one ear would get red; very flushed; a vein would stick out.” The parents reported seeing this “a lot when he was younger.”

Subject #7- Unable to tolerate many things going on around him and becomes easily irritated. Easily over-stimulated; used to get red cheeks.

Subject #8 – “He used to get purple ears.”

Subject #9 - “Loses it!” “Had red cheeks when little.

Subject #10 – He was wiggly and had difficulty focusing; could not handle being over stimulated.

F.b) Was there anything you could do to help him with this?
Subject #2 - The parent reported that Mom was the one that needed to comfort him when he was upset. When he was upset his parents could tell because "he sucks his thumb and bites his nails."

Subject #4 - The parent reported that physical activity would help reduce the anxiety but he would get over stimulated if he had too much (physical activity). "(It is) best not to over-react to what he says or does because the situation gets elevated."

Subject #6 - The parent explained that they "...had to get him to look at you" to get his attention when a lot was going on in the environment.

Subject #7 - The parent explained, "He didn't like groups of people and would go off by himself."

Subject #8 - The parent explained that he was not keen on being hugged and "scream(ed) like a wounded lion."

Subject #10 - The parent explained they had to remove him from the situation.
14. How does your child respond when you give him / her directions?

All ten of the children (100%) were identified by parents as having problem areas when given directions. The participating parents made the following comments:

Subject #1 - "Needs cuing and not too many steps at once."

Subject #2 - "I must be very clear & precise. He does not extrapolate well. I frequently need to check for understanding."

Subject #3 - "Initially as if he did not hear me – 2nd/3rd time with louder voice he responds most of the time!"

Subject #4 - "Depends on focus, mood, environment stimulus."

Subject #5 - "Sometimes it was hard getting his attention."

Subject #6 - "Somewhat non-responsive."

Subject #7 - "Can only do one [to] two steps at a time – becomes overwhelmed with multi-step tasks."
Subject #8 - “Any more than one step he is lost.”

Subject #9 - “Any more than one step he is lost.”

Subject #10 - “Sometimes [we] need to work on getting his attention.”

15. How does your child respond to simple questions?

Seven out of the ten children (70%) were identified by parents as having inconsistencies in their responses when asked simple questions. Two of the children [Subjects 3, 6] required repetition in order to generate a response. Subjects #2, #5 and #8 had difficulty with certain “types” of questions (e.g., trick, yes/no, choice.) For two children [Subjects 1, 7] in the group their mood was reported to affect the response. The participating parents made the following comments:

Subject #1- “Depending on mood, is able to give very clear, detailed response.”

Subject #2 - “No problem unless it is a ‘trick’ question.”
Subject #3 - "Sometimes he doesn’t respond until asked a second time – other times immediately he is interested in topic/person.

Subject #4 - "Ok."

Subject #5 - "Yes/no questions – echolalic response for yes/no response for no."

Subject #6 - "Needs to be asked more than once."

Subject #7 - "Often ignores people talking to him – if you persist he may become irritated, especially if occupied."

Subject #8 - "Not well in making choices."

Subject #9 - "Indirectly."

Subject #10 - "Appropriately."

16. How would you describe your child’s intelligence or thinking skills?

Eight out of the ten children (80%) were reported by parents as being “very/highly/extremely intelligent.” The parents of the other two children (20%) reported that their child was cognitively
challenged (e.g., had difficulty with abstract concepts) with one adding that his intelligence/thinking skills were, "choppy – poor."
The participating parents made the following comments:

Subject #1 – "Extremely intelligent, highly verbal, with gaps (some distinct learning disability areas), such as written expression and math computation."

Subject #2 – "Above average – superior [based on recent testing.] He’s brilliant! Social skills has always been the problem.

Subject #3 – "Very intelligent – constantly thinking about ‘why’ things happen – often very stuck on abstract concepts. Excels at reading comprehension. Always needs improvement with social skills and pragmatics."

Subject #4 – "Very Smart – Deficits in theory of mind, social skills, [and] coping strategies."

Subject #5 – "Very bright, curious, good problem-solving – learns by asking questions. Learns explicitly. He has an excellent memory."

65
Subject #6 - "High. Mechanically inclined; can look at something and put it together; loves science. Anything he’s into he excels at!"

Subject #7 - “Does not have ability to comprehend stories – can’t verbally repeat back to you (and) often responds inappropriately. Struggles with cognitive issues.”

Subject #8 - “Extremely bright, quite bright – it’s just getting to it! One day he’s on and the next day he’s off (and you) can’t get anything out of him.”

Subject #9 - “Choppy - poor; cognitively challenged”

Subject #10 - “Above average. We didn’t have another child to Compare with but he continually amazed us with his intelligence and awareness.”

F. How would you describe his learning style?

Four out of the ten children (40%) were reported by their parents as learning “literally” or “explicitly.” The remaining parents described a variety of learning styles or deficits (e.g., auditory, hands-on, applies self only when interested, rote-memory, poor short-term memory.)
17. Describe the kind of sounds your child made before one year of age – cooing prolonged vowel sounds, babbling repeated syllables, squealing, etc.

Eight out of the ten children (80%) were described by their parents as making typical or normal sounds (e.g., babbling raspberry sounds, cooing, squealing, repetitive sounds, some words) with one parent adding that their child was an “early talker.” The three remaining report the following sounds: “uncertain” (due to adoption), “squealing/screaming/unable to speak or mimic sounds due to hearing impairment,” and “echolalic or rolling vowels.”

18. Was there anything unusual about the sounds your child made during this period? If you answer “yes” to this question, please explain.

Eight out of the ten children (80%) were reported by parents as not making unusual sounds while two children (20%) did. The parent of one of the latter children said “he sounded Asian & very monotone” and the other parent explained “he grunted a lot.”

19. When did your child say his/her first real word?
The range of responses included the following: “Fairly early, seven months, eight to nine months, ten months, one-year, one-year to eighteen months, three to three and a half years, and four and a half years.” There were two parents that did not respond and one that responded “not sure.”

20. Did your child continue to add new words on a regular basis?

If you answer “no” to this question, please respond to a and b below.

Nine out of the ten children (90%) were reported to add words on a regular basis with only one child not regularly adding words.

a. How often did your child add a new word?

The parent of Subject #7 explained that he was hearing impaired and did not have his first real word until after a year of speech therapy at age four and a half years.

b. Did your child frequently use another way to communicate?

According to the parent, Subject #7 would “point to what he wanted, scream, & grunt” to communicate.

21. Did your child’s speech or language development seem to stop
for a time? If you answer “yes” to this question, please respond to a and b below.

Three out of the ten children (30%) had speech or language development stop for a time.

a. When and why do you think it stopped?

The parent of the three children referred to above responded with the following comments for sections a and b:

Subject #6 - “(His) pronunciation came slowly.”

Subject #7 - “(He had) no interest in talking; (he was) used to other forms of communicating.”

Subject #9 - “We stopped sensory integration for a time.”

b. How did your child communicate with you during this time?

Subject #6 - “Verbally, we had difficulty understanding his words.”

Subject #7 - “Scream, grunt, point, single syllable words.”

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22. When did your child first put two or three words together?
   The response range for eight of the subjects reported by parents was twelve months to four and a half years with two parents “not sure.”

23. When did your child begin to use more complete sentences?
   The response range for eight of the subjects reported by parents was fifteen months to six years with two parents “not sure.”

24. How many different words is your child saying now?
   This question is not applicable as all of the children are currently over the age of three.

25. Do you consider your child to be talkative or quiet?
   Two of the children (20%) were considered by their parents to be both talkative and quiet. Two more of the children (20%) were considered quiet (occasionally very talkative) by their parents. The remaining six children (60%) were considered by their parents to be talkative which included “making lots of sounds.”
26. How does your child usually let you know what he/she wants?

*If you answer with “pointing” or “gesturing” to this question, please respond to a and b below.*

Seven out of the ten children (70%) were reported to verbally let them know what they wanted and added that, “[he] acts out aggressively.” Two of the children (20%) were reported to point and use single words and one adds that, “if he wanted something he’d just go get it.”

**a. Does your child try to talk in combination with pointing?**

Three or four of the participating parents made the following comments about their child in sections a and b.

Subject #4 – “Yes, [he] uses single words.”

Subject #7 - “[He] screams [& uses] single words.”

Subject #9- “[He] waves his hands.”

**b. Does anyone in the family talk for your child or interpret his/her gestures?**

Subject #4- “No.”
Subject #7 – Mother reported: “I did when he would try to communicate with friends & family who didn’t understand him.”

Subject #8 – If there is difficulty understanding intent, “mom is always there to correct misunderstandings.”

Subject #9 – “We all interpret.”

27. Has your child ever talked better that he/she does now?

    If you answer “yes” to this question, please explain.

    This question is not applicable as all of the children are currently over the age of three.

28. Do you think your child’s speech is normal for his/her age?

    If you answer “no” to this question, please respond to a, b, and c below.

    Six out of the ten children (60%) were reported to have normal speech for their age with parent of Subject #1 noting her child had “some difficulty with social language.” The parent of Subject #5 responded “yes” but answered the questions below. Four out of the
ten children (40%) were reported to have abnormal speech for their age.

a. How well do you understand your child’s speech?

Four to six of the participating parents made comments in sections a, b, and c:

Subject #4 - “Very well (Articulation); high vocabulary.”

Subject #5 - “Well.”

Subject #6 - “We need to remind him to slow down and not mumble.”

Subject #7 - “Fairly well.”

Subject #9 - “Pretty good.”

b. How well do people outside the family understand your child’s speech?

Subject #4 - “Very well (Articulation); high vocabulary.”
Subject #5 - "More difficulty understanding (his) intent."

Subject #6 - "With some difficulty."

Subject #7 - "Not well at all."

Subject #8 - "Difficulty understanding (his) intent."

Subject #9 - "Not well."

c. How does your child react if he/she is not understood by others?

Subject #4 - "Frustration, sarcasm, blames others."

Subject #5 - "Just repeat(s) himself."

Subject #6 - "Annoyed."

Subject #7 - "Becomes very frustrated - screams, cries."

Subject #9 - "Acts out."
29. Do you have any concern about the way your child’s tongue or mouth works for speech or for eating? If you answer “yes” to this question, please describe.

Parents of two out of the ten children (20%) reported being concerned about the way their child’s tongue or mouth works for speech or eating. These two parents made the following comments for this question:

Subject #5 - “Some gag reflux (at) approximately three years old.”

Subject #8 - “He was tongue-tied; it was fixed at the dentist office...had to be taught at birth to suck on a bottle.”

F.a) Did your child have strong food preferences, aversions, eating issues at ages birth to three?

Eight out of the ten children (80%) were reported as having strong food preferences, (“hard & crunchy stuff,” “white food,” “smooth and crunchy”) aversions (“mushy or lumpy food,” no texture combinations) or eating issues (minimal and inconsistent appetite) during this stage of development.
30. What concerns you most about your child's speech or language skills now?

All ten of the children (100%) were described by their parents as having problems in the area of "social expression" or "conversation" (e.g., "social skills, coping skills, self-soothing"). Two parents also added that their child would "speed (talk very fast)/rattle off quickly" or would mumble/mutter." A third parents' concern was, "how upset he gets when he can't express his needs," while a fourth parents’ concern was that "he can’t get his thoughts out clearly."

31. What have you done to help your child learn to talk?

Parents of eight out of the ten children (80%) reported taking the following actions to help their child learn to talk:

"Talked with him a lot, read a lot; visuals - visual schedule, (taught) him how to answer questions, continue(d) to remind him to slow down & not mumble, encourage(d) him to "use his words"; speech therapy support when he became frustrated, sensory integrations; adaptive devices; sign language; and repetitive exercises. There was no response from two of the participating parents."
32. Has anything about your child's speech or language development seemed unusual to you? If you answer "yes" to this question, please describe.

All ten of the children (100%) were reported by their parents as having something about their speech and language development that seemed unusual.

F. Can you explain to me how his speech or language development was unusual?

All ten of the participating parents responded with the following comments about their children:

Subject #1 - "'Little professor'-enunciated very precisely & clearly, used vocabulary and sentence structure way beyond his peers."

Subject #2 - "He received some speech therapy when younger (in an Early Intervention program). Prosody varied and unpredictable; occasionally will "rattle off or mumble."

Subject #3 - "His vocabulary is quite advanced - even if he sometimes mispronounces a word."
Subject #4 - “Was very aggressive, increased amount of tantrums (when) over-stimulated (and) did not get his way. More monotone (speech) at a younger age than it is now. Rapid speech (is) still a problem for him. Had better inflection (back) then when he was younger.”

Subject #5 - “An early talker...for yes/no questions he would have an echolalic response for “yes” and a “no” response for “no.” Not “conversational.” Vocabulary consisted of labels (that were) not very functional. Consider(ed) more “talkative” than quiet but less so at school. People outside the family have more difficulty understanding his intent.”

Subject #6 - “(Had a) slower pace than classmates and siblings... pronunciation came slowly and it was difficult to understand his words. Very fast rate of speech & “mumbling” quality. (Had) to be reminded to slow down and still does not properly pronounce. Described as “talkative.” Becomes annoyed when he is not understood by others... dyspraxia problems still ongoing... (a) motor planning issue.”
Subject #7 - “Very slow. Could not speak until he was four years-old. Chronic ear infections so after (he) had tubes put in he began to speak. He was so frustrated that he would scream constantly. He had no words or definitive sounds and had speech therapy after getting the tubes in. Did some sign language when he began speech therapy.”

Subject #8 - “Said his first words at seven months, said “hi Dad.” Freaked us (Mom & Dad) out! Talks in his sleep now. Multi-tasking is out of the question. Looks at the ceiling when he’s talking to you. Mumbles at night when he’s tired; he has a soft, soft way of talking unless he’s pissed-off.”

Subject #9 - “Did not speak first words until he was four and a half years old...flat when singing. Has always had monotone speech...it’s very neutral...he doesn’t clear his throat - I have to tell him to swallow...When he had a sore throat he used to say ‘fire’.”

Subject #10 - “Never told me when he was cold, hot, or hungry. At two years old he had a friend over to play and (he) said, “Joshie home?” and I said “oh, no he’s going to stay and play with you for a little while.” He got his point across! Knew alphabet and counting
because I sang to him when I spent hours rocking him to sleep...had some lullabies... He knew the Pledge of Allegiance at two, maybe almost three. He was putting short phrases together and (some) full sentences...his communication ability was more than average but I do not have another child to compare him to...rote memory for scripts."

33. How much time does your child spend with other children?

Five out of the ten children (50%) were reported by their parents to spend minimal time (e.g., not enough, very little, not very much) with other children. Parents of two of the children (20%) responded that when small they had frequent play dates/play groups. Parents of two more of the children (20%) reported that time spent with other children was (mainly in) school. The remaining parent answered for their child’s "current" age, therefore the response was not appropriate for this research.

F.a) Sharing-how did he do as a young child (birth to three) compared to his peers?

Parents of seven out of the ten children (70%) reported their child did poorly with sharing (e.g., "very possessive," "sharing was a problem," "had some trouble"). Parents of two of the children
(20%) reported typical sharing behavior, and the remaining parent did not respond to the question.

F.b) Are there any unusual daycare/play experiences that you recall from when he was between the ages of birth to three?

All ten of the parents answered this question making the following comments:

Subject #1 - “Friends were always children of other women that I was friends with. Birthday party invites stopped and he did not care but I did. He wanted to do his own thing rather than play the games at birthday parties. He was terrified of being left at preschool...did not know how to play with other children.”

Subject #2 - “Personal body space; did not understand...social skills and organization always a problem. Very friendly...but always in people's faces. He attended part-time preschool two days, three days, and then Kindergarten and had no separation problems. Made a wonderful attachment to his teacher; really, really great!”

Subject #3 - “From birth to three he was in a private daycare with other infants and his sister. At about age four he began to play
alone more on the daycare playground and had trouble with sharing and the chaos and noise of the environment.” He would often cling to one or two favorite teachers.

Subject #4 – “Had to leave groups because of his behavior. Until he was four or five, if someone or something came within two feet of him, he would hit them. Very upsetting for Mom as she was socializing and they would have to leave because he could not handle it. People are not accepting of this.”

Subject #5 – “He was in a nursery school at the age of two so I got to see him compared to the other children. This was helpful in understanding that he was different.” His nursery teacher helped to pick-up on things and told Mom she was concerned about him for next year.

Subject #6 – “Preschool teachers told us that ‘he never uses his words’ but was aggressive and would push peers out of the way. “Weird” thing he did was to lock a kid in a shed & never tell anyone that he was there. He was thrown out of two preschools...had to have an aid with him because of behavior (the) adult to age ratio too large for him. He did not know how to interact with the kids.
Forcing him to take a nap did not work - he never napped!!! Would keep getting up at school and make noises.

Subject #7 - Mom does not recall any unusual play experiences with him, but "he did seem to prefer to play alone."

Subject #8 - "...Preferred to be off by himself; it took a long time to participate in group activities...he would just go off."

Subject #9 - "Began early intervention and went to preschool at two and a half years old. Bus ride has always been a nightmare because he’d be going one way and what he wanted was the other way (Mom)."

Subject #10 - "He had an aide five mornings a week, three mornings a week at preschool and then he had daycare... Not really interested in playing with kids in nursery school. The teachers recommended he get evaluated for help with social skills. Didn’t really play with other kids he just did his own thing."
F.c) What was the childcare arrangement from birth to three?

Seven out of the ten children (70%) were cared for by their mother who was home full-time from birth through at least age three. Two parents responded that their child was in private daycare. The remaining participant did not respond to the question.

F.d) How was your child’s interaction with peers?

Parents of four out of the ten children (40%) reported that he “just did his own thing” or “played alone.” Parents of two of the children (20%) responded that he “never had any friends.” Parents of three children in the group (30%) reported that their child had a “small group of friends” who experienced similar social difficulties. Parents of two of the children (20%) reported that their child exhibited aggressive behavior in social peer groups.

34. Does anyone in the family have a history of any speech or language problems?

*If you answer “yes” to this question, please describe.*

Parents of two of the ten children (20%) indicated there was a family history of speech or language problems. The parent of Subject #4 reports that there is an uncle with undiagnosed Asperger Syndrome. The parent of Subjects #8 and #9 (who has two children
in the study] reported that almost all the males on maternal side of family have a “speech thing” (e.g., lisp, stutter, dyspraxia). Parents also responded with the information listed in Table 5 (Family History of Subjects) regarding family history of Asperger syndrome, Autism Spectrum Disorders, and Speech/Language disorders.

Table 5

Description of subjects' family history regarding Asperger syndrome, Autism Spectrum Disorders, and Speech/Language disorders as reported by parents.

<table>
<thead>
<tr>
<th>Subject</th>
<th>Family History</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td>Biological father diagnosed Bi-polar; suspect has undiagnosed AS; suspect paternal grandfather has; No S/L undiagnosed some type of ASD; No S/L</td>
</tr>
<tr>
<td>#2</td>
<td>Suspect biological father has undiagnosed AS; suspect paternal uncle has undiagnosed AS; No S/L</td>
</tr>
<tr>
<td>#3</td>
<td>Father has some common traits, No S/L</td>
</tr>
<tr>
<td>#4</td>
<td>Suspect maternal uncle undiagnosed AS, Yes S/L</td>
</tr>
<tr>
<td>#5</td>
<td>No on mothers side; unknown on fathers side, No S/L</td>
</tr>
<tr>
<td>#6</td>
<td>Suspect one maternal cousin may have ADHD/ADD</td>
</tr>
<tr>
<td>#7</td>
<td>Biological father reported as undiagnosed AS; some S/L deficits as well.</td>
</tr>
<tr>
<td>#8</td>
<td>Biological father reported as undiagnosed AS; Bi-polar &amp; OCD</td>
</tr>
<tr>
<td>#9</td>
<td>Father reported as undiagnosed AS; Bi-polar &amp; OCD</td>
</tr>
<tr>
<td>#10</td>
<td>Birth mother ADHD &amp; OCD (suspect undiagnosed AS) Sister diagnosed Autism</td>
</tr>
</tbody>
</table>

F.a) Smells - Was he sensitive or bothered by any when younger (birth to three)?

Five out of the ten children (50%) were reported to be sensitive or bothered by smells and another two children (20%) were reported to be somewhat sensitive or bothered. The remaining three children (30%) were not sensitive or bothered by smells.
F.b) Sounds - Was he sensitive or bothered by loud noise/s when younger (birth to three)?

Nine out of the ten children (90%) were reported to be sensitive or bothered by loud noises with the remaining parent of Subject #2 (10%) explaining, “If anything, he is not very sensitive to sounds...has virtually no startle reflex.”

35. List any other specialists who have seen your child:

The following is a compiled list of responses from the ten participants.

**Medical** - Occupational Therapist, Physical Therapist, Speech Therapist, Neurologist, Pediatric Neurologist, Neuro-Psychologist, Pediatric MD & Family Practitioner, Pediatric Developmental MD, Psychiatrist, Psychologist

**Hearing** - Audiologist, Ear Nose & Throat MD, Surgeon

36. What information about your child would you most like to get from this evaluation?

The following is a compiled list of responses from the five participants that wrote a response:
Summary of Results

Objective #1

Identify/verify previously reported common communication and behavioral traits in very young children with AS.

The common communication and behavioral traits among the study population were substantial. These included speech and language development characteristics (includes social/conversational skills), energy levels, and early attachments (people and toys).
Speech and Language Development Characteristics

Questionnaire and interview results indicate that all of the ten parents reported that there was something about their child’s speech or language development that seemed unusual between ages birth to three. Parents related a range of factors that they identified as being unusual that they observed in their children. The one common identified factor was the lack of social or conversational skills. Interestingly, the lack of social or conversational skills was a problem for all of the children whether they were an “early talker” or had “slow development” of speech. These findings suggest that the characteristics of speech and language development in children from birth to three is relevant to early identification of AS.

Sixty percent of the children (Subjects 5, 6, 7, 8, 9, 10) were described as being “talkative” or “making lots of sounds” by their parents from birth to the age of three. Twenty percent of the group, (Subjects 2, 4) were described as being “quiet” and only “occasionally very talkative” while parents of the remaining two children (Subjects 1, 3) said their sons were both “talkative” and “quiet” at times. The speech and language development characteristics reported by parents are summarized in Table 6 (Speech and Language Development Characteristics).
Table 6

Speech and language development characteristics of ten children with Asperger's Syndrome from birth to three as reported by parents.

<table>
<thead>
<tr>
<th>SUBJECT:</th>
<th>#1</th>
<th>#2</th>
<th>#3</th>
<th>#4</th>
<th>#5</th>
<th>#6</th>
<th>#7</th>
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<th>#9</th>
<th>#10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advanced vocabulary</td>
<td>+</td>
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<tr>
<td>Enunciated precisely</td>
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*At 4 years-old

The remainder of the Rossetti questions regarding Speech and Language Development (i.e., 16, 17, 18, 19, 21, 22, 23, 29) were less remarkable. Eighty percent of the children made typical or normal sounds before one year of age. Only Subjects #7 and #9 exhibited atypical sounds. The range of ages reported for the children saying their first real words for the eight other Subjects [1, 2, 3, 4, 5, 6, 8, 10], was seven months to eighteen months. The parents of Subjects #7 (three to three and a half years) and #9 (four and a half years) reported their children as
saying their first real words when much older. The range of ages reported for the children putting two or three words together and using complete sentences followed the same type of pattern with the exception of Subjects #7 and #9. Ninety percent of the children in the group continued to add words on a regular basis except for Subject #7.

Seventy percent of the children (Subjects 1, 2, 3, 5, 6, 8, 10) let their parents know what they wanted using their words. Three of the remaining children (Subjects 4, 7, 9) utilized single words or physical actions to communicate their wants (e.g., aggression, pointing, go get what want). Several of the parents indicated that they often had to talk for their child (Subjects 7, 8, 9) or interpret his gestures so that others could understand the intent.

Thirty percent of the group did have speech or language development stop for a time. Two of these children (Subjects #7, #9) had previously identified speech and language issues. The parents of Subject #6 reported that their child's pronunciation was slow in developing and they had difficulty understanding his words.

Overall, the parents of sixty percent of the children (Subjects 1, 2, 3, 5, 8, 10) were of the opinion that their child's speech was normal from
birth to three. The remaining forty percent (Subjects, 4, 6, 7, 9) were described as having abnormal speech. Though only four out of the ten children were categorized as having abnormal speech, several parents of children (Subjects 5, 8) from the “normal speech” group answered the follow-up Rossetti questions. Interestingly, the issue of concern for Subjects # 5 and # 8 was related to communication intent rather than speech. When parents were asked how well people outside the family understood their child’s speech, three responded and (Subjects 6, 7, 9) referred to speech. Parents for four of the children (Subjects 4, 6, 7, 9) reported that their child reacted negatively if not understood by others and these were the same four described as having abnormal speech.

**Social/Family Times**

Seventy percent of the children showed interest in the people and things around them. There were no particular problems with meeting strangers for ninety percent of the children compared to their peers. All ten of the children exhibited some behaviors that were disruptive during family time. The reported behaviors correlated with the issues that parents had already identified as problematic in other areas of the child’s life. Ninety percent of the children were reported as being “easily confused” when there were many things taking place around them. Parents attributed some of these reactions to noise, anxiety, over-
stimulation, and difficulty focusing due to the activity level. To help their child cope with the confusion one of the parents would comfort him, another would have to get his attention and "...get him to look at you" while a third would remove him from the situation.

All ten of the children were reported by their parents as having difficulty in their response to directions. Four in the group (Subjects 3, 5, 6, 10) were somewhat non-responsive and parents had to work to get their attention. Three children (Subjects 7, 8, 9) had particular difficulty with multi-step directions and two others needed clear, precise directions with cuing to help with follow-through. Subject #4 was inconsistent in his response when given directions depending on various factors (e.g., mood, focus, environment.)

In response to simple questions, seventy percent of the children were identified as having inconsistencies in this area. Two of the children (Subjects 3, 6) required repetition in order to generate a response. Subjects #2, #5, and #8 had difficulty with certain "types" of questions (e.g., trick, yes/no, choice.) Mood was reported to affect the responses of two children (Subjects 1, 7) in the group.
Energy Levels

Questionnaire and interview responses indicate that all ten of the children exhibited high energy levels in some form when compared to their peers. When examined in relation to emotional factors, the coping abilities of these children with AS are problematic.

- Seven out of ten children (Subjects 1, 4, 5, 6, 7, 8, 9) were difficult to calm and reported as having high frustration levels.
- Nine of the ten children (Subjects 1, 2, 3, 4, 5, 6, 8, 9) were reported by their parents as seeming active as opposed to seeming inactive. Eight of these children were described as having “high energy” with four referred to as “hyper” (Subjects 4, 7, 8, 9). Though one of these eight was reported as inactive because he, “Would often drift off in thought.” Three out of ten children were reported as “very restless” (Subjects 4, 6, 9). Two of the group were reported as having “average” energy levels (Subjects 2, 3) but not as seeming inactive.

Early Attachments

All ten of the children were reported by their parents as being “most closely attached to their mother.” From age birth to three, seventy percent of the children were cared for by their mother who was at home full-time. Nine of the children were never separated from their parents for
a long period but the tenth was due to adoption. Eighty percent of the group had an early attachment to either a blanket or a favorite stuffed animal. Forty percent of the children preferred to be at home over other environments.

**Objective #2**

Identify any unique characteristics observed by parents of very young children with Asperger syndrome as compared to typical children.

There were some characteristics parents observed that stood out as being somewhat unique for the study group when compared to the typical child. These included sensory issues, play with toys/peers, bedtime or sleeping issues, and possibly color preference.

**Sensory Issues**

Questionnaire and interview results indicate that all of the ten child subjects experienced some type of sensory issue from birth to three. The sensory areas included either a hyper or hypo response to smell (7/10 positive), sound (9/10 positive), taste/food consistencies (8/10 positive), touch (9/10 positive).
Smell

Seven out of ten child subjects were reported to be sensitive or bothered by smells. Half of the child subjects were reported as being very sensitive or bothered by smells with two additional children reported as being somewhat sensitive or bothered by smells.

Sounds

Nine of the children were reported by parents as being sensitive or bothered by loud noises as compared with their peers. The tenth child was described as being not very sensitive to sounds and having “virtually no startle reflex.”

Taste/Food Consistencies/Eating Issues

Eight of the children were reported as having strong food preferences, aversions or eating issues from ages birth to three. Detailed responses were mixed and did not indicate any patterns of preferences, aversions or eating issues. Parent recall and reporting of strong food preferences seemed more detailed than those of either aversions or eating issues.
Touch

Hyper - Three resisted cuddling (7,8,9) and a total of four exhibited overall increased touch sensitivity (4,6,7,8). Four liked deep pressure (1,2,3,9) and one had an aversion to brushing teeth, toenail & fingernail clipping (10) with his parent reporting that "he loved swimming...gets a lot of sensory input with the jumping in...he doesn’t seem to mind the cold water either...child never reported being “hot, cold, or hungry” which raises the question of possible reduced sensory awareness (hypo).

Clothing- Eight were quite particular about the clothing that they would choose or agree to wear. Two of the children preferred loose clothing while six were bothered by the feel of certain fabric or seams. In particular, soft clothing was described as being strongly preferred by five of the eight children.

Play

Many of the parents (eighty percent) reported several ways that their child’s play was atypical. These included playing with toys and peers.
Toys

Seven out of ten children (Subjects 4, 5, 6, 7, 8, 9, 10) were reported by parents as playing with toys in an unusual manner. An additional parent described play scenarios, which could be considered atypical even though the parent answered “no” on question ten of the Rossetti. During the interviews, all nine parents described special interests that their child/children had. Even though three parents answered “no” to “unusual play with toys,” they still identified interests that their child had that were atypical. Additionally, six out of the ten examples described by parents who answered “yes” had strong similarities. All six children played with toys in a repetitive manner by lining-up the objects, making patterns and designs, or watching patterned movement of an object.

Peers

Parents of all ten children reported that play with peers was problematic. Fifty percent reported their child spent minimal time with other children. Two parents stated that their child (Subjects 1, 7, 8, 10) “just did his own thing” or “played alone.” A couple of parents explained that their child (Subjects 2, 7) “never had any friends.” Having a small group of friends who had similar social difficulties was the situation for three more of the children (Subjects 3, 8, 9). Two children (Subjects 4, 6) exhibited aggressive behavior in social peer groups.
• **Sharing** – Seventy percent of the children were thought to have more difficulty sharing when compared to their peers.

• **Unusual social experiences** – There were several factors raised by parents that were problematic during peer social interaction for their child. Four of the subjects (2, 7, 8, 9) did not understand “personal body space” and this made play experiences problematic. Another child (Subject 3) “had trouble with sharing and the chaos and noise of the environment.”

**Bedtime/Sleeping Issues**

Nine out of the ten children (Subjects 1, 2, 3, 4, 6, 7, 8, 9, 10) had some type of bedtime or sleep issue. More than half had difficulty settling down to go to sleep (6/10) while others received “calming input” prior to going to sleep (2/10) or had ritualistic bedtime (1/10). Fifty percent of the children had a history of night terrors and for two of these children the episodes were frequent and serious over an extended amount of time. Only one child (5) was reported by his parent to have no issues with bedtime or sleeping.

**Color preference**

Curiously, three of the children (Subjects 2, 4, 7) preferred the color red while one (Subject 8) had an aversion to the color red. Three of the
children (Subjects 1, 9, 10) had “no preference” for color. Though an interesting angle in this study, the relevance or lack of relevance to the early diagnosis of AS is unknown and unexplored. Further research would be necessary to understand if the forty-percent preference/aversion for the color red has any true merit or if this was a “fluke” occurrence. Comparison of color preference between children with AS and typically developing peers would also need to be assessed and analyzed.

**Objective #3**

Collect data from parents of AS children concerning perceived strengths and weaknesses of their child exhibited from birth to three years of age.

Parents shared information about their children from age birth to three that indicated perceived areas of strengths and weaknesses. Areas that parents perceived as problematic included transition issues, emotional issues, motor skills (fine and gross). Areas of strength included intelligence/thinking skills.

**Transition Issues**

Fifty percent of the group were described as having the ability to intensely focus on an activity and become immersed in what they are doing to the exclusion of everything and everyone around them. Parents
identified this as being problematic because their child was hyper-focused when compared to the focus levels among other children of the same age. This exasperated focus on activities of high, personal interest contributed to problems with transitioning between activities. Problems with transition were reported for nine of the ten children during birth to three (exception is # 5 whose issues with transition did not become apparent until after the age of three). The majority of parents remarked that their child did “better with routines” (Subjects 2, 3, 4, 7, 8, 9, 10) and that changes in the routine created problems. One parent insightfully explained, “They can’t be (think) like us – we have to be (think) like them. We (parents) know what works – we know what doesn’t work. Forcing them to be normal... they are normal for them. They have to have time to change gears on their terms.”

**Emotional Issues:**

- Eight children were described as anxious or having difficulty with frustration (Subjects 1, 2, 3, 4, 6, 7, 8, 10) while two had aggressive or violent behaviors (Subjects 4, 9).
- Five parents observed that during times of anger, frustration, or over-stimulation their children (six total) exhibited either a red face, ear/s, or cheeks (3, 4, 6, 7, 8, 9).
Seven children (1, 3, 4, 7, 8, 9, 10) in the study had fears or strong dislikes and for five of these children (3, 4, 7, 8, 9) this was a significant issue. Interestingly, all of the latter five were in the group that exhibited a physical trait (e.g., red face, ear/s, cheeks) when they were feeling angry, frustrated, or over-stimulated.

Motor Skill Issues:

Results of this research indicate that assessment and observation of both gross and fine motor skills are important in the diagnosis of AS. Eight of the ten children (1, 3, 4, 5, 6, 7, 8, 10) were identified by their parents as having "poor" fine motor skills. In contrast, the reported range of gross motor skills was divided among three levels. Three of the children (1, 9, 10) had "great" gross motor skills, three had "okay" (2, 3, 5) and the remaining four (4, 6, 7, 8) were in the "poor" category. Only one of the subjects (9) were reported as having "excellent" fine and gross motor skills. It should be noted that Subject 9 had the most significant cognitive, speech, and language issues among the ten children and arguably could be identified as being the lowest functioning child within the group.

Between the ages birth to three, only one of the children (Subject 2) sucked his thumb. Five of the children exhibited some form of tic behavior with four having hand/finger flapping (Subjects 2, 4, 7, 8) and one having
repetitive sounds (10). Parent of Subject #6 explained that, "He’s always
got something in his hands and is always fidgeting."

**Intelligence/Thinking Skills:**

Eighty percent of the children were described by their parents as
very/highly/extremely intelligent (Subjects 1, 2, 3, 4, 5, 6, 8, 10). The
parents elaborated on their child’s intelligence by describing areas of
cognitive strengths and weaknesses. One parent noted, “Anything he’s
into he excels at!” Another parent mentioned, “He continually amazed us
with his intelligence and awareness.” A third parent remarked, “He has an
excellent memory.” Six of the eight parents described areas of difficulty
their children struggled with despite the high levels of intelligence. Three
parents (Subjects 2, 3, 4) remarked about problematic social skills while
one (Subject 1) reported on difficulties with written expression and math
computation.

Twenty percent of the children (Subject 7, 9) were reported as
being cognitively challenged (e.g., had difficulty with abstract concepts)
with one also having “choppy-poor” thinking skills. There were a range of
learning styles reported but forty percent of parents said that their child
learns literally or explicitly. Another parent described their child as follows,
“One day he’s on and the next days he’s off (and you) can’t get anything out of him.”

**Objective #4**

Observe behavioral traits and characteristics with respect to communication skills of very young children who are later diagnosed with AS.

The final objective was not assessed because none of the participating parents prepared videos for the researcher to view. Several parents did "watch" some early video tapes of their child and shared their observations during the interview portion of the study. It is difficult to determine what information or how much information may have been available if parents had provided the video tapes. Direct viewing of the children via videos by the researcher would have furnished a means to confirm or question the information that parents gave in both the questionnaire and interview. Observations made by the researcher would have been subjective and introduce possible personal biases of the researcher.
CHAPTER IV

DISCUSSION

The intent of this research was to identify possible early communication and behavioral characteristics in children from birth to three years who were later diagnosed with Asperger Syndrome. The researcher hypothesized that a cluster of common characteristics would emerge and that these could be utilized as "red flags" in suspect infants and toddlers up to age three. The identified communicative and behavioral "red flags" could serve as a screening tool and lead to subsequent recommendations for an extensive evaluation with the appropriate professionals. Earlier screening tools could result in earlier diagnosis and the provision of needed appropriate services at a far earlier age than has typically been the case.

The results of this investigation indicate that evaluating behavioral and communication characteristics of infants and toddlers may constitute a viable screening tool for Asperger Syndrome. In particular, assessment of speech and language development is an important area to identify
atypical characteristics in children birth to three. The population evaluated in this study had atypical characteristics of speech and language development that ranged from advanced to delayed skills. Although participating parents categorized more than half the children as having normal speech from birth to three, atypical characteristics were reported for all ten of the subjects. These findings support the hypothesis that children with AS can and do exhibit speech and language differences though the “delays” or “unusual” factors may be quite subtle. On their own, these speech and language differences may not appear to be substantial but when combined with the other identified behavioral characteristics discussed in this research, they become significant “red flags.”

In addition to the lack of social or conversational skills noted by parents, all ten of the children had difficulty in their responding to directions. Whether due to decreased focus, decreased social awareness, decreased auditory processing, or “being in their own world” all subjects exhibited significant problems in this area. In addition, seven children out of the group also had inconsistencies responding to simple questions.
The results of this research strongly indicate that assessment of behavioral characteristics is also a viable way of screening for Asperger Syndrome. High energy and high frustration levels were a predominant theme. Seven of the subjects were difficult to calm when anxious or upset and this was reported as a significant issue by their parents. Certain social situations were also problematic such as disruptive behavior during family time, confusion or over-stimulation in busy environments, and intense focus on activities of high interest regardless of the surrounding environment. The latter point included a "lack of response" to communication attempts by others.

As a whole, participating parents identified several areas that appeared to be unique for this AS population when compared to the typical child. All of the children in the study group experienced some type of sensory issue and were either hypo or hyper sensitive to smells, sounds, taste/food consistencies, or touch. Several other behavioral characteristics possibly unique to the AS population were identified and described in this investigation. Parents reported atypical play with both toys and peers, issues with bedtime or sleep, and preference/aversion for the color red.
Parents described several other areas that were particularly problematic for their children. Transition between activities was challenging and parents determined that routines were extremely helpful for the majority of the subjects. Either fine or gross motor skills were an area of difficulty for ninety percent of the children in the study. It should be noted that fine/gross motor skills may have been viewed as an area of comparative strength in the tenth subject as cognitive, speech, and language concerns were predominant weaknesses. Review of transitional behaviors and fine/gross motor development would be beneficial for assessment of possible AS in children birth to three.

Research Implications

Continued research is needed to confirm the need for testing in all of these identified areas. The limitations in this study are considerable in that participating parents had to rely mainly on memory to report on communication characteristics and behaviors of their child with AS. Furthermore, interpretation of the parent reported data, (both Rossetti Questionnaire and interviews) was performed by the same researcher who conducted the interviews. Though inter-rater reliability measures were instituted in the procedures of this study, it is impossible to fully eliminate personal biases.
The researcher found the Rossetti Parent Questionnaire a valuable instrument for use in this research project. The questionnaire was designed specifically for parents and covered areas of communication development that were relevant to this study. The Rossetti format imposed a structure for carrying out the face-to-face interviews. There were several concerns that arose during use of the Rossetti. When filling out the questionnaire prior to the interviews parents frequently misinterpreted some of the questions (Numbers 6, 10, 11, 13, 34). During the interview discussions parent earlier responses were clarified and (with parent permission) consequently changed on the form. Also noted by the researcher were a lack of questions regarding “sensory issues” on the Rossetti. The use of the Rossetti Parent Questionnaire as part of a complete infant/toddler assessment battery could be enhanced by the addition of “sensory” questions.

Future research projects should evaluate a larger population of children between birth to three based on these identified areas and conduct a longitudinal study to determine the children who are later identified with AS. Early assessment results of the children could then be compared to the entire population in later years. Further research in these areas would provide more definitive and validated guidelines for screening children between ages birth to three.
The areas of assessment identified in this research are the result of written responses to the *Rossetti Parent Questionnaire* and in-depth interviews (including in-person, telephone conversations, and emails) with parents. The researcher cautions against the exclusive use of a checklist format to assess children birth to three years of age. Interpretation of written questions can vary between parents and inconsistencies in responses lend to misdiagnoses. Only through discussion, clarification, observation, and careful consideration between the parent, child, and professional can a true picture and understanding of the young child emerge. Areas of communication and behavioral characteristics reported in this study are best suited for screening purposes to identify children who may benefit from undergoing a diagnostic process with the appropriate professionals.
LIST OF REFERENCES


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Stoles, S. (2000). *Children with Asperger’s Syndrome: Characteristics/Learning Styles and Intervention Strategies*. "Written by Susan Stokes under a contract with CESA 7 and funded by a discretionary grant from the Wisconsin Department of Public Instruction."


APPENDIX A

Submitted to IRB for Approval

Early Identification of Children with Asperger Syndrome: Communication Characteristics

I. Introduction

The prevalence for the diagnosis of Asperger’s Syndrome (AS) in children and adults has increased substantially since the 1994 inclusion of AS in the DSM-IV and ICD-10. AS is widely thought to be on the autism spectrum disorder (ASD), sharing the same cluster symptoms as autism disorder (AD) and considered “high functioning autism” (HFA) by many. The bulk of the research regarding early identification of ASDs has focused on the population diagnosed with AD. Though there are significant similarities in diagnostic criteria, there are distinctive differences between AS and AD. There is an impressive existing body of materials and markers for early identification in children suspected of having AD (Adrien et. al., 1993; Baird, 2003; Kline, 2004; Gillberg, 1990; Wing, 1993). Currently, very little exists in the way of early diagnosis materials or markers for AS. Consequently, diagnosis is not typically made until the child is in the school-age years (Kline, 2000; Sicile-Kira, 2004; Yee, 2005). This research study is designed to explore the early childhood years from birth to age three of children who are later diagnosed with AS and add to the existing body of knowledge.

Wetherby and Woods state that empirical research is compiling evidence of the effectiveness of intensive early intervention for a substantial proportion of children with autism spectrum disorders (ASD). Successful interventions use a range of behavioral and naturalistic approaches, which have a much greater impact when provided before age 3½ compared to after age five. They contend that this underscores the importance of improving early identification, noting that there are still no biological markers therefore screening and diagnosis must be based on behavioral features (2003). Speech and Language therapy is one of the key providers of early intervention services to children ages birth to three as mandated by Part C of the Individuals with Disabilities Education Act (IDEA) first instituted in 1986 (Lipinski, et al.). According to the American Speech-Language-Hearing Association (ASHA), “speech-language pathologists and audiologists provide more than half of all services under the IDEA program. Communication skills, language and
literacy abilities define the very core of learning and set the course for school success."

This retrospective study is designed to gain further insight into what early characteristics can be identified in children from birth to three years who are later diagnosed with AS. Information gathered will further the understanding of the early years of these children and perhaps contribute to the early identification of AS. Administration of a standardized procedure for examining language development between birth and three years will be accompanied by open-ended interviews with parents who have children with AS. The latter will provide narrative information that can help us recognize observable characteristics or behaviors that may exist in this population.

II. Objectives

- Identify/verify previously reported common behavioral traits in very young children with AS.
- Identify any unique characteristics observed by parents of very young children with AS.
- Collect data from parents of AS children concerning perceived strengths and weaknesses of their child from birth to three years of age.
- Observe behavioral traits and characteristics with respect to communication skills of very young children who are later diagnosed with AS.

III. Research Protocol

A. Setting/Participants: Eight to twelve adults that are parents of a child diagnosed with Asperger's Syndrome according to the DSM-IV will be recruited from northeastern New England. The participants' children with AS will be between four and eighteen years of age. Participants will be obtained through word-of-mouth and referrals from the UNH Seacoast Child Development Clinic, Asperger's Association of New England NH Chapter, and Hampshire Country School in Rindge NH. An introduction and recruitment letter will be supplied to obtain consent from parents. The Rossetti Infant-Toddler Language Scale will be mailed prior to conducting one-hour interviews. Interviews will be conducted and audio taped at participants' home. Researcher will review any material e.g. video tapes, baby books, journals, and prior reports that document communication skills of the children from birth to three years of age. Parent and child anonymity will be maintained with code; materials and data will be locked in a cabinet.
B. Investigator Experience: Please refer to attached faculty advisor’s letter.

C. Protocols: Parents will be asked to answer the Rossetti Infant-Toddler Language Scale and engage in an open format, audiotaped interview regarding early memories of their child diagnosed with Asperger’s Syndrome (AS). The attached interview questions will be mailed or emailed to willing participants prior to meeting to encourage reflection. The open-ended interview questions will be supplemented by non-scripted and non-biased questions based on information that may become available during conversation with the parent. Materials documenting or recording communication skills of the child subjects will be reviewed and qualitatively analyzed. Variables, common and unique themes will be identified and analyzed. For reliability purposes, audiotapes will be transcribed and 25% of the data will be reviewed by raters who will be asked to agree or disagree with researcher’s findings. For inter-rater reliability two, second year graduate students with a Bachelor of Science in Communication Sciences and Disorders will rate the data. Ongoing supervision will be provided by the thesis committee, chaired by Dr. Stephen Calculator.

D. Consent Procedures:
   1. Introductory letters and consent forms for the study group provided.
   2. Parents fill out consent forms to participate in the study, discuss their child’s early childhood experience in interview, and provide early communication materials of child.
   3. Copies of consent forms and assent waiver attached.

IV. Data

Data will be analyzed using qualitative methodology. Researcher will examine each child’s communication development since birth in the following areas: interaction & communication, comprehension & understanding, and speech & language. Anonymity of participants will be maintained through use of pseudonyms during recording of data and reporting of data. Researcher will document interview data on site with conversation tape-recorded simultaneously. All data will be stored in a securely locked cabinet. Access to data will be available only to researcher and faculty supervisor, with the exception of audiotape transcripts that will be reviewed by raters. Upon conclusion of the study, all materials will be returned to participants and cassette tapes will be destroyed within six months of the study. Researcher hopes to describe common communication characteristics that are unique to the AS group that can be used for early identification of AS children. Since little exists in
the way of past research for early identification of this population, any information contributing to the current body of knowledge is welcome and may provide direction for future research.

V. Risks
No foreseeable risks are associated with this study beyond the maintenance of confidentiality. Confidentiality will be maintained with pseudonyms and securing of materials. Data will be number coded for identification purposes.

VI. Benefits
Benefits are nominal to the parents and reliability raters in this study. There will not be any financial compensation provided. Possible benefit to participants may be generated in the sharing of memories and experiences about their child with AS, as well as contributing to the quest for increased understanding of the early diagnosis of children with AS.
APPENDIX B

Submitted to IRB for Approval

REQUEST IRB WAIVER OF ASSENT OF CHILDREN

There will be no children participating in this study. No direct or indirect level of interaction will occur, I thus request a waiver of assent as it would not serve any function.
INFORMED CONSENT DOCUMENT
(Administered to parents of children with Asperger’s Syndrome)

Lynda D. Chouinard, B.S.
Graduate Student, Communications Sciences & Disorders
Hewitt Hall, University of New Hampshire
Durham, NH 03824-35653

Dear Ms. Chouinard,

As a parent of a child with Asperger Syndrome (AS) I wish to participate in your research project entitled, “Early identification of children with AS: communication characteristics.” I understand that the primary purpose of this investigation is to explore the early childhood years to gain insight into what early communication characteristics can be identified in children from birth to three years of age who are later diagnosed with AS. This interview will be carried out in my home and will be simultaneously audiotaped. I further understand:

1. This project will begin on or around September 1, 2005 and continue until January 30, 2006. However, my participation will only be necessary for the time needed to complete the Rossetti Infant-Toddler Language Scale, provide materials e.g. video tapes, baby books, journals, and prior reports that document communication skills of my child from birth to three years of age, and participate in a one-hour interview.

2. The study procedures do not involve any foreseeable risk for me or my child. Pseudonyms will be used to maintain confidentiality for my child and myself.

3. Results of this investigation may be submitted for publication consideration. Neither my name nor my child’s name will be used at any time and the confidentiality surrounding my child’s participation will be maintained to the greatest extent possible.
4. My participation in this research study is voluntary; refusal to participate will involve no penalty or loss of benefits to which my child and I are otherwise entitled.

5. I may discontinue my participation in this study at any time without penalty or loss of benefits to which my child and I are otherwise entitled.

6. If I have questions about this research I should contact Lynda D. Chouinard by mail, phone (603.548.6178) or email at lyndac@cisunix.unh.edu. I can also contact Dr. Stephen Calculator, thesis advisor and Professor of Communication Sciences & Disorders, by phone (603.862.3836) or email at Stephen.calculator@unh.edu.

7. If I have any questions related to my rights as a research subject, I can contact the University of New Hampshire’s Office of Sponsored Research at 603.862.2003.

__________________________  ____________________________  ____________
Signature                  Print Name                     Date

Address: ___________________________ Phone: ____________

__________________________ Email: ____________
APPENDIX D
Submitted to IRB for Approval

INFORMED CONSENT DOCUMENT
(Administered to Raters)

Lynda D. Chouinard
Graduate Student, Communication Sciences & Disorders
Hewitt Hall, University of New Hampshire
Durham, NH 03824-35653

Dear Ms. Chouinard,

I wish to participate in your research project entitled, “Early identification of children with Asperger Syndrome: communication characteristics.” I understand that the primary purpose of this investigation is to explore the early childhood years to gain insight into what early communication characteristics can be identified in children from birth to three years of age who are later diagnosed with AS.

1. This project will begin on or around September 1, 2005 and continue until January 30, 2005. However, my participation will only be necessary for the time needed to review audiotaped interview data that has been transcribed. It will involve no more than 10 hours of my time over the duration of the project.

2. Results of this investigation may be submitted for publication consideration. My name will not be used at any time and the confidentiality surrounding my participation will be maintained to the greatest extent possible.

3. My participation in this research study is voluntary; refusal to participate will involve no penalty of loss of benefits to which I am otherwise entitled.

4. I may discontinue participation in this study at any time without penalty or loss of benefits to which I am otherwise entitled.

5. If I have questions about this research I should contact Lynda D. Chouinard by mail, phone (603.548.6178), or email at lyndac@cisunix.unh.edu
6. If I have any questions related to my rights as a research subject, I can contact the University of New Hampshire’s Office of Sponsored Research at 603.862.2003.

Signature ___________________________ Print Name ___________________________ Date ______

Address: ______________________________ Phone: __________________________

_____________________________ Email: __________________________
May 2, 2005

Chouinard, Lynda
Communication Sciences & Disorders, Hewitt Hall
181 Harantis Lake Road
Chester, NH 03036

IRB #: 3443
Study: Early Identification of Children with Asperger Syndrome: Communication Characteristics
Approval Date: 05/02/2005

The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved the protocol for your study as Exempt as described in Title 45, Code of Federal Regulations (CFR), Part 46, Subsection 101(b). Approval is granted to conduct your study as described in your protocol.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the attached document, Responsibilities of Directors of Research Studies Involving Human Subjects. (This document is also available at http://www.unh.edu/osr/compliance/IRB.html.) Please read this document carefully before commencing your work involving human subjects.

Upon completion of your study, please complete the enclosed pink Exempt Study Final Report form and return it to this office along with a report of your findings.

If you have questions or concerns about your study or this approval, please feel free to contact me at 603-862-2003 or Julie.simpson@unh.edu. Please refer to the IRB # above in all correspondence related to this study. The IRB wishes you success with your research.

For the IRB,

Julie F. Simpson
Manager

cc: File
    Stephen Calculator

Research Conduct and Compliance Services, Office of Sponsored Research, Service Building, 51 College Road, Durham, NH 03824-3585 * Fax: 603-862-3564

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