

LOST IN TRANSLATION:
THE EARLY IDENTIFICATION OF ASPERGER SYNDROME

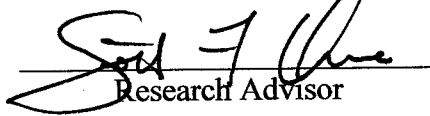
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ABSTRACT

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<u>Lost In Translation: A Case Study of Asperger Syndrome</u>			
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Early identification is essential in maximizing our intervention outcomes for children with Asperger syndrome (AS). The research consistently shows the benefits of early detection, followed by the appropriate early intervention. The benefits extend not only the child, but also to the family, educational and medical community, and society as a whole. This chain of positive outcomes undoubtedly begins with the identification process; for only after effective and efficient diagnoses methods are developed for AS can we properly achieve later successes in treatment. A review of literature uncovers a need for a universal system of detection, possibly beginning directly in the medical community where early developmental checks are already customary for children. Currently, there are several methods by which professionals screen for AS, however; this variability contributes to the lack of consistency in diagnosis. This study intends to

develop a comprehensive screening device, which outperforms the variability of options available. Through this implementation, the hope is to get these children the help they need as soon as possible. Research consistently seems to indicate - the faster the child receives intervention, the better.

TABLE OF CONTENTS

	Page
ABSTRACT.....	ii
Introduction.....	1
<i>Purpose of Study</i>	9
<i>Significance of Study</i>	10
Chapter II.....	11
Review of Literature	11
<i>Early Identification</i>	11
<i>Interdisciplinary Team</i>	14
<i>Benefits of Early Identification</i>	15
<i>Assessment instruments</i>	16
<i>From Identification to Intervention</i>	18
Chapter III.....	20
Summary and Implications	20
<i>Strengths of the Paper</i>	21
<i>Limitations of the Paper</i>	21
References.....	22

Chapter I

Introduction

His temperament as an infant was described as near perfect; yet, as first time parents, the couple would have tolerated any degree of colicky behavior. As a toddler, his verbal ability and language development were phenomenal. He was arguably ahead of most, if not all, of his same-aged peers, meeting developmental milestones on a seemingly daily basis. He was reading and speaking in simple sentences by the age of two. This advanced ability overshadowed any growing concerns about his increasingly awkward behaviors; his insistence upon sameness in furniture arrangements, his hyper-intolerance of bright lighting, and his eventful tantrums.

By age three, his parents were no longer able to overlook the dramatic changes. He became distant, as if he was a world away and void of emotion. The once engaging toddler, who often smiled and rarely cried, was suddenly replaced by a seemingly empty body, absent of his smile, eyes constantly fixed in a blank stare, looking past or through them. The little boy who once gave long hugs and filled the kitchen with lingering laughter was replaced so suddenly with a quiet complexity, a condition later identified as Asperger syndrome (AS).

This scenario illustrates the reality associated with autistic-like diagnoses, which are increasingly getting more attention as the prevalence rates continue to rise. According to Bashe and Kirby (2001), "Most authorities place the incidence of AS somewhere around 1 in 250 and 1 in 500. However, because AS is still an under-diagnosed condition, it may be more prevalent. One thing we do know is the rate of diagnosis of autism,

Asperger's Syndrome, and 'pervasive developmental disorder-not-otherwise-specified,' a catchall term for diagnosis that don't need exact criteria, has increased dramatically over the past decade" (p. 12). Safran and Safran (2001) predict, "it may well become the fastest-growing disability group of the early 21st century" (p. 386). This growth undoubtedly deserves attention.

According to the Diagnostic and Statistical Manual of Mental Disorder, Fourth Edition – Text Revision (DSM-IV-TR), pervasive developmental disorder (PDD) is the umbrella category for six underlying specific disorders, characterized by severe impairments in several developmental areas, including; social interactions, communication skills, and stereotypical behaviors. The six specific disorders include: Asperger syndrome (AS), autistic disorder (autism), pervasive developmental disorder-not-otherwise-specified (PDD-NOS), Rett's disorder, childhood disintegrative disorder, and Fragile X Syndrome. Three of the above mentioned disorders are further described within a subcategory: autistic spectrum disorders (ASD), which includes AS, autism, and PDD-NOS.

Upon further examination, there is a controversy in the field as to whether this autistic spectrum disorder "breakdown" is legitimate. Some experts agree the link between these three disorders (AS, autism, and PDD-NOS) is largely justifiable, based on continuum of "autistic" symptoms and evidence of hereditary susceptibility to ASD's (Bashe & Kirby, 2001, p. 18). However, there are also activists that disagree, arguing that the differences between the three disorders (AS, autism, and PDD-NOS) far outweigh the similarities. This paper will follow the notion of Bashe & Kirby (2001); "For better or worse, autism is a highly charged term that communicates that the person's condition is

serious and that his or her ability to communicate effectively is severely compromised” (p. 22). Therefore, if the specific disorders continue to be classified as such, the current society tends to better understand the implications. Also, in further attempt to be consistent with the research, the terms *autism* and *Asperger’s Syndrome* are considered related disorders. Whether or not one is a form of the other is not specified in the present paper.

People commonly refer to these conditions in popular culture terminology; “mind-blindness,” “the geek syndrome,” “social dyslexia,” and “social blindness.” In technical terms, these all describe variations of autism. According to the M.I.N.D. Institute (2002), autism is more accurately described as, “a neurological or brain disorder that profoundly affects a person’s ability to communicate, form relationships with others, and respond appropriately to the environment” (p. 6). More specifically, as outlined by the DSM-IV-TR, autism is identified by the presence of several characteristics, including impairment in social interactions, communication irregularities, as well as evidence of repetitive behaviors, interests, or activities (APA, 2003).

Despite research efforts, the etiology of autism is not yet proven; “the causes of autism remain largely unknown and no treatments that affect the core symptoms have been developed.” (Brown University, 2004, p. 1). There are several hypotheses speculating the causes of autistic-like disorders, including suspicions about childhood vaccines, nondairy diets, and environmental toxic agents (Cowley, 2000). However, “The one thing that almost all researchers in the field agree on is that genetic predisposition plays a crucial role in laying neurological foundations of autism in most cases. Studies have shown that if one identical twin is autistic, there’s a 90 percent chance that the other

twin will also have the disorder” (Silberman, 2001, p. 179). In addition, “Autism occurs in males three to four time more frequently than females” (MIND, 2002, p. 10).

Unfortunately, the scientific information is limited at this time, and is in its early stages.

Historically, the disorder’s causes were presumed to a direct result of cold parenting, but this hypotheses has long since been abandoned; “Although Asperger’s – and autism in general – was once believed by many doctors to be the result of poor parenting, scientists now know that it is caused by deficits or delays in the development of the part of the brain normally involved in social reasoning” (Kase, 2001, p. 144).

There is increasing attention to brain structure differences, as Cowley (2001) states; “Autopsies of autistic people have found that cells in the ‘limbic’ regions that mediate social behavior are often small and densely packed, suggesting their early development was interrupted” (p. 51). Unfortunately, there is no sound evidence of any cause(s) precipitating the onset of autistic spectrum disorders.

As previously stated; “An incidence of autism, like that of learning disabilities, attention deficit hyperactivity disorder (ADHD), asthma, diabetes, arthritis, chronic fatigue syndrome, inflammatory bowel disease and other autoimmune and neurological disorders, has risen dramatically in the U.S. and other technologically advanced countries” (National Vaccine Information Center, n.d.). According to the M.I.N.D. Institute (2002), “prevalence estimates have been in the range of 10-12 per 10,000” (p. 10). This is alarming statistical information, considering the supposed increases in prevalence rates since 2002. Thus, the issues of PDDs, ASDs, autism, and AS all combine to form one very serious concern, regardless of the category or the cause.

According to Bashe and Kirby (2001), coauthors of *The OASIS guide Asperger Syndrome*, “Asperger Syndrome differs from other pervasive developmental disorders in that those children who have it usually hit major developmental milestones on time or even early” (p. 11). According to the DSM-IV-TR, persons with AS, unlike those with autism, do not show significant delays in language nor cognition. Safran (2002), an associate educational psychology professor and avid researcher of AS, concurs; “With average to superior intellectual capacity, the child with Asperger’s looks typical but lacks the social awareness and skills needed to connect with his or her world” (p. 60). In reference to the introductory scenario, AS diagnosis occurs without warning, in the midst of a seemingly normal, even advanced, development.

By common reference, “Asperger Syndrome has historically been connected with the more widely used term autism” (Myles & Simpson, 2002, p. 2) and reiterates the decision to use both terms in this discussion. Asperger Syndrome is commonly referred to as high-functioning end of the autism spectrum continuum, or a milder form of autism (Barnhill, 2001). Said another way, Safran (2002) suggests, “It has been said that while the autistic child lives in a world of his own, the child with Asperger’s lives in his world but within ours. Lacking both the skills to blend in and the visible disability that might signal a need for understanding, this child is truly alone” (p. 61). Therefore, comparing disorders to determine which is worse seem redundant and incredibly useless. As Bashe and Kirby (2001) state, “It is important to remember that Asperger Syndrome is a serious, lifelong disability that requires individualized expert intervention and should be treated as such. There is nothing ‘mild’ about the challenges people with AS face” (p. 27).

There is a certain level of ambiguousness in AS criterion; “Technically, you can identify AS by the symptoms, behaviors, and deficits that constitute the diagnostic criteria, but it’s almost impossible to extrapolate from that information what it means to have AS” (Bashe & Kirby, 2001, p. 9). There is therefore no easy AS definition or one all-inclusive picture to paint of a person with the disorder. There are individual variations; with reference to the concept that no two people possess the exact same characteristics (Safran, 2002). In addition, “There is no ‘one thing’ a person with AS may have that is exclusive to AS. Asperger syndrome is identified and defined by the pattern of its presentation- the symptoms, behaviors, strengths and deficits- not by its ‘cause’” (Bashe & Kirby, 2001, p. 16). Again, Asperger Syndrome is diagnosed through observation, not through biological means.

AS presentation includes, but is not limited to: social impairments, verbal/nonverbal communication impairments, restricted range of interests or rigidity toward sameness, as well as possible others (motor, academic, emotional, sensory, and theory-of-mind difficulties). Myles and Simpson (2002) indicate the those with AS, “typically have average to above-average intellectual abilities, are motivated to be with their general education peers, and have good rote memory skills and other assets that bode well for their educational success” (p. 134). However, they also note, “Children and youth with AS are typically thought to be socially stiff, socially awkward, emotionally blunted, self-centered, deficient at understanding nonverbal social cues, and inflexible” (2002, p. 132). Therefore, people with AS are likely very aware of their unique characteristics.

The greatest challenge of people with AS appears to be within the social context; “Although individuals with AS desire social contact, they repeatedly fail, due to this overall inability to understand the social culture. In school, they are often children without friends, picked last for any group or team, who exasperate the teacher with inappropriate questions or contradictions and just do not seem to ‘get’ what is going on” (Safran, 2002, p. 284). Their social deficits affect other areas of life, due to the interrelatedness of the symptoms involved. For example, Myles and Simpson (2002) refer to social challenges along with a generalized sense of rigidity; “When children and youth learn social conventions, they often try to apply them universally. However, social conventions are variable, making them difficult to rigidly and consistently apply” (p. 133). A more practical example from Barnhill (2002):

“One student reflected: You know how you ‘get it’ if I’m upset and know right away what to do to help me out? Well, I can’t do that. If you were upset, I would have to input all the data, like you were crying or something, and then figure out in my brain what it means. Then I would have to figure out what I was supposed to do” (p. 63).

Communication is another major challenge for those affected by AS. Bashe and Kirby (2001) warn parents, “Even though your child may be sophisticated in her expressive language (what she says), most persons with AS have ‘hidden’ yet deep and pervasive deficits in their understanding of what is communicated to them, through the use of words (semantics and pragmatics) and the flow of nonverbal information we transmit constantly though tone, rhythm, inflection of voice; body language; facial expression; and gaze modulation” (p. 45). Therefore, they appear, or sound, as if they

should know more than they actually do. Myles and Simpson (2002) add, “Students with AS are generally thought to have particular difficulty in comprehending abstract materials (e.g., metaphors, idioms); understanding inferentially based materials; and applying skills and knowledge to solve problems” (p. 134). In other words, the statement “don’t read a book by its cover” is taken literally.

According to Barnhill (2002), “The restricted range of interests found in persons with Asperger Syndrome can take unusual or eccentric forms” (p. 262). People with AS frequently fixate, or obsess over a particular topic. Little (2002) adds, “A child with Asperger’s will simply memorize everything there is to know about a certain and sometimes bizarre topic” (p. 3). The topic of interest varies greatly; “No pattern has been found in the forms of special interests that have been selected by individuals with AS; however, they are diverse and encompass such subjects as geology, astronomy, mechanics, numbers, and fabrics” (Myles & Simpson, 2002, p. 134). This may not seem atypical considering some of eccentric interests of modern-day children; “While their obsessive interests are similar to the interests of typically developing children, they are unlike other children in that their restricted interest is the only activity in which they participate” (Barnhill, 2002, p. 262).

There are also a number of other characteristics typical, but not necessary provisions of an AS diagnosis. Kirby (2003) states, “Often overly sensitive to sounds, tastes, smells, and sights, the person with AS may prefer soft clothing, certain foods, and be bothered by sounds and lights no one else seems to hear or see” (p. 1). There are often emotional and behavior problems associated with the persons knowledge of their own obvious differences; “students with AS typically have behavior problems connected to

their inability to function in a world they see as unpredictable and threatening” (Myles & Simpson, 2002, p. 133). Again, the presentation of AS varies. One particular article alluded to a commentary made between professionals about a student with Asperger’s: “I overheard one exasperated educator exclaim, ‘It’s so hard to be Brian’s teacher!’ A colleague quietly replied, ‘Think of how hard it is to be Brian.’” (p. 65). Despite our own frustrations, as Barnhill (2002) suggests, we need to strive to, “Separate the child from the syndrome and try to experience the world through his eyes” (p. 63).

Aside from the obvious implication of a diagnosis, there is an enormous personal effect on both the individual and their families. Silberman (2001) states, “Autism’s insidious style of onset is particularly cruel to parents, because for the first two years of life, nothing seems to be wrong. Their child is engaged with the world, progressing normally, taking first steps into language. Then, suddenly, some unknown cascade of neurological events washes it all away” (p. 177). Despite the wealth of information about AS, families are still faced with the difficulty of acceptance. As Cowley states (2001), “It’s not hard to see how mindblindness would derail a person’s social development. If you can’t perceive mental states, you can’t show empathy, practice deceit or distinguish a joke from a threat- let alone make friends” (p. 50). For families, understanding the disorder is only a fraction of their journey.

Purpose of Study

The purpose of this study is to review the literature relevant to early identification of individuals with Asperger syndrome. The study will focus on describing programs and studies that use well-designed assessment techniques. The following are objectives of the review:

1. Explore the benefits of early identification
2. Describe the process and implications.
3. Review research of programs or clinics that conduct early identification programs.
4. Identify key components of early identification methods in order to develop a user friendly instrument.

Significance of Study

The significance of this study relates to the importance in understanding the implications of early identification on an individual with Asperger Syndrome. Given the research on early detection, it is essential that educators understand both the process and the implications. In addition, it is important to assess how the current processes affect the child, family, and educational staff to gain a greater understanding of improvements needed in this area.

Chapter II

Review of Literature

The review of literature suggests Asperger Syndrome is somewhat difficult to diagnose early on in life, when developmental processes are merely beginning. Beauchesne and Kelley (2004) agree; “Although autism by definition must begin in early infancy, it often remains unrecognized and undiagnosed until or after late preschool for many reasons” (p. 57). There are obvious problems with waiting, as one mother explained, “I had the doctor telling me that every moment counts. There’s that horrible feeling of time slipping away and nothing being done” (Tarkan, 2002, p. 3). Diagnosis deserves a careful use of time and available resources; however, the message certainly appears to be- the faster the better. In the most basic sense, Dr. David L. Holmes, president of the Eden Institute, an autism center in Princeton, said, ““If you have a child with autism who’s not wired correctly, and we allow that to continue without intervention, those neuropathways will become fixed, and it becomes far more difficult to undo that tangled mess”” (Tarkan, 2002, p.2).

Early Identification

According to Brown University (2004), “probably around 20% of children show normal development for a period of time and then regress” (p. 6). This statistic only adds to the difficulty of diagnosis, according to a 1994 study, “less than a third of children with serious developmental or behavioral disabilities were detected by their primary health care provider before entering school. Other studies have shown that a simple observation and parent questionnaire can double or triple the number of children

detected” (Beckstrom, 2004, p. 1). A significant number of children are undetected due to the early developmental progress, an illusion of “normalness,” while the remaining seems to be slipping past detection due to unsatisfactory detection tactics.

To further complicate this analysis, not only is detection complicated; as Robert L. Beck, the President of the Autism Society of America, states ““Parents, physicians, and researchers all agree that early diagnosis permits early intervention which produces lifelong benefits to individuals and to society. However, too many children with autism are not diagnosed until they reach school age”” (Brown University, 2004, p. 3).

Essentially, we are all in agreement that early intervention is a key contributor to later successes, but all in the midst of the challenges of early diagnoses. Campbell & Morgan (1998) extend, “As with autism, early diagnosis that leads to preschool behavioral programming may increase chances for later adjustment. Individualized services are strengthened by taking advantage of the relatively normal development in cognitive and propositional language abilities of children with AS” (p. 71).

The M.I.N.D. Institute (2002) states, “Treatment successes for some children diagnosed early and treated intensively have increased attention toward making the diagnosis of autism as early as possible” (p. 6). The challenge is largely to become better at the initial phases of AS detection; “Since it is imperative to intervene early with these children to achieve optimal improvements, it is essential that parents and providers be aware of these early signs. Early suggestive indicators of autism include deviant play behavior, impaired imitation skills, early parental concern, and deviance versus delays in development” (Beauchesne & Kelley, 2004, p. 58). Early intervention appears to be critical for individuals with AS; therefore, “it is important that educators, families, and

physicians have a comprehensive understanding of this complex exceptionality” (Myles & Simpson, 2002, p. 132).

Though parents are an excellent resource in early diagnosis, the responsibility does not solely lie with them; “School districts across the country are reporting dramatic increases in the number of students with Asperger Syndrome and High Functioning Autism (HFA), requiring many communities to scramble to establish programs and services for the ever burgeoning population with pervasive developmental disorders” (Kaufman, 2002, p. 1). Myles and Simpson (2002) note, “Only recently has AS been showing up on the educational radar. Ever-increasing numbers of children and youth are being identified with the disorder, and teachers, administrators, counselors, and other educational professionals are quickly discovering that children and youth with AS are extremely challenging to serve effectively” (p. 135). Attention to autistic spectrum disorders is largely on the forefront of many disciplines; “It’s all part of an increased national focus on autism spurred by families angered that the disorder has long been sparsely funded despite studies suggesting a 10-fold rise in cases in a decade” (*Brain Scan May Unlock Autism Mysteries*, 2004).

The initial problem appears to lie within the identification process. Baron-Cohen (2002) summarize, “No specialized screening tool exists and most primary healthcare professionals have little training in the detection of autism as toddlers. However, the earlier a diagnosis can be made, the sooner family stress can be reduced; moreover, intervention can improve the outcome” (p. 521). Likewise, Filipek et al. (2000), explains, “The diagnosis of autism often is not made until 2 to 3 years after the symptoms are recognized, primarily because of concerns about labeling or incorrectly diagnosing the

child” (p. 469). It appears that professionals are in a Catch-22; we are dually concerned about misdiagnosing too early and diagnosing too late.

Current diagnosis depends on specialized professionals regardless of setting. Within the schools; “Assessments are typically carried out to assign a diagnostic label or to determine placement eligibility. Domains such as communication, cognitive ability, social skills, and motor development are often of interest to the school psychologist. The ultimate goal of assessment, however, is to provide opportunities for helpful educational planning” (Fitton & Ford, 1998, p. 2-3). There are others who suggest a more medically-based assessment of autism spectrum disorders; “Young children should be screened for autism just as they are for vision and hearing problems, a new report by the National Research Council (NRC) urges, because early diagnosis is the key to overcoming its effects” (NCD, p. 3).

Interdisciplinary Team

Best practice suggests that early identification is a joint effort, from a team of professionals. As Fitton and Ford (1998) suggest, “Interdisciplinary assessment has been touted as the optimal format for diagnostic decision-making for most school referrals, but it is truly essential in making a diagnosis of autism” (p. 3). This, however, adds to the complication of time constraints. According to the Minnesota Department of Children, Families and Learning (2002), “In the world of autism, time is critical. In study after study, research had consistently demonstrated that early identification of autism and intensive intervention leads to improved results” (p. 7). The Minnesota Department of Children, Families & Learning has developed a statewide program entitled- Check for

Autism Really Early (CARE), a plan to improve early identification of autism in young children.

CARE was initiated to address the very problem of discussion: “Minnesota is experiencing a growing prevalence of autism such that every health care provider and every school can expect to serve children with autism. Minnesota’s existing education, social service, and health care systems are not effectively identifying autism during the preschool years when interventions are most effective” (Minnesota Department of Children, Families, & Learning, p. 1). The goal is largely to increase early identification in order to optimize early intervention strategies. The program is based on two concepts: (1) all children should be screened for atypical development, and (2) children already identified as at-risk should be further evaluated to specify the individual’s needs.

Benefits of Early Identification

The benefits to early identification are numerous. Research supports that early intervention leads to improved outcomes with children with AS. However, “not only beneficial from a social, education and health care perspective, it is cost-effective as well” (Minnesota Department of Children, Families, & Learning, 2002, p. 9). For example, early screening for young children increases further successes, therefore, requiring less money for intensive therapies. Likewise, early detection benefits families as well (Minnesota Department of Children, Families, & Learning, 2002); “Continued stress, caused by the child’s needs, limited understanding of the disorder, limited community supports and diminished hopes for improvements, often result in divorce, escalating use of social services and child placements by age 14” (p. 10). In addition, parent training and family support will be initiated earlier in the process.

Assessment instruments

In addition, worksheets like the Checklist for Autism in Toddlers (CHAT) have been developed as a screening tool for autistic-like tendencies (Baron-Cohen et al., 2000). More specifically, this particular checklist focuses on the presence (or lack of) two significant behaviors: joint attention and pretend play. Joint attention is defined as- “the ability to establish a shared focus of attention with another person,” while pretend play is- “the attribution of imaginary features to people, objects or events” (p. 521-522). According to Baron-Cohen and associates (2000), both of these characteristics are typically delayed in children with autism. The CHAT involves nine questions for the child’s parent(s), as well as five personal observation items. The pilot findings suggest that CHAT is a clinical screening tool primarily for high-risk autism, with only a 50% chance, at best, of identification those screened at medium and low risk. Due to the “normal” presentation of children with Asperger syndrome, it is likely that these children are not identified at an early age as “high-risk.”

Another widely-used identification instrument is the Autism Behavior Checklist (ABC), which is a component of the Autism Screening Instrument for Educational Planning, containing 57 items and 5 subscales: sensory, relating, body and object use, language, and social and self-help (Eaves, Hollie, Campbell & Chambers, 2000). Evaluators simply check whether or not a specific characteristic is present in the child of interest. Limitations of this particular instrument include validity and reliability concerns. The Pervasive Developmental Disorder Rating Scale (PDDRS) is yet another identification instrument, comprised of 51 items and three subscales, including: arousal,

affect and cognition ((Eaves, Hollie, Campbell & Chambers, 2000). Evaluators are to rate the individual child on a 5-point Likert scale according to the degree to which the individual exhibits the particular behavior of interest. Again, many studies examining the effectiveness of such scales have similar limitations, including a questionable population of individuals used in the study, as well as lack of knowledge about the initial diagnoses of their participants.

Aside from checklist-type identification procedures, there are several other options. Ikeda (2002) states, “The acronym RIOT is helpful in identifying assess methods that could be used in assessing Autism: (a) Review of reports and records, (b) Interviews of significant caregivers, (c) Observations of the child in the natural setting, and (d) Testing of the child” (p. 1502). Records and reports offer a great deal of information about the child’s behavior over time. Reviewing past information can offer evidence of specific concerns, such language delays, etc. Parent (or other caregiver) interviews are helpful in determining the antecedents or response to the behavior, and a better general understanding of the conditions that surround the behaviors of interest. The assumption is that no one knows a child better than his or her parents do.

Observations of the child in their natural environment can prove enormously helpful. According to Ikeda (2002), “Behavior observations help in identifying and verifying things such as: (a) the extent to which child plays with other children his or her age, (b) initiation of social interactions thorough sharing of toys, and (c) response to attempts of children or adults to initiate an interaction with the child” (p. 1503).

Checklists, such as CHAT, PDDRS, and ABC also assist in behavioral assessments, as

well as testing in some circumstances, which involves the use of standardized tests to document and diagnose specific deficits in comparison with the norm group.

The goal associated with the program, as well as screening instrument is to identify and activate appropriate accommodations for these children; “Early diagnosis of autism and early intervention facilitates earlier educational planning, provisions for family supports and education, management of family stress and anguish, and delivery of appropriate medical care and treatment” (Filipek, 2000, p. 469). However, there is a need for a more successful measure in identification of Asperger syndrome. According to CHAT (2002):

Screening is only as valuable as the tools used are sensitive and reliable predictors of autism. Unfortunately, ‘fewer than 30% of primary care providers conduct standardized screening tests (in the rigid manner for which they were intended) at well-child appointments. Those that do screen for developmental issues generally utilize screening instruments that research has revealed to be sufficiently sensitive or specific to reveal most developmental disorders (p. 9).

If there is better, and more universal way, to identify AS, we can improve services overall, starting at the optimal time in a child’s development.

From Identification to Intervention

Our efforts can then, and only then, focus on the search for appropriate interventions, after the proper identification has been completed. Likewise, this task offers its own complications; “The list of intervention options for children and youth with autism is ever increasing, and this serves only to exacerbate the problem of professionals’ and parents’ abilities to choose the most efficient and effective treatment methods”

(Heflin & Simpson, 1998, p. 194). Myles and Simpson (2002) also contend, “Individuals with this complex disorder give every indication of having needs that can be addressed effectively only when trained professionals correctly use a variety of appropriate methods in an individualized fashion” (p. 135).

There are many aspects to consider in the development of appropriate programs; “The educational community and families of students with AS have been challenged to implement effective supports and interventions for these students, despite the lack of clear understanding of the disorder and without empirical direction as to the educational methods that are most suitable” (Myles & Simpson, 2002, p. 132). Despite the many challenges, “On the bright side, these children can often do quite well in supported general education placements if sufficient care is given to adequately educating all staff members with whom they will come in contact about the nature of the syndrome and the best way of helping them in school settings” (Kaufman, p. 7). The task of finding the appropriate learning environment for children with Asperger Syndrome is a challenge, but an achievable goal. Perhaps Safran (2002) stated it best; “If we really believe that no child should be left behind, then we have no choice but to persevere in our efforts to ensure that all the students who pass through our doors believe that they belong with each other and with us” (p. 65). This means we have to locate them faster.

Chapter III

Summary and Implications

Early identification is essential in maximizing our intervention outcomes for children with Asperger syndrome. After an extensive review of the literature, the research consistently shows the benefits of early detection, followed by the appropriate early intervention. The benefits extend not only the child, but also to the family, educational and medical community, and society as a whole. This chain of positive outcomes undoubtedly begins with the identification process; for only after effective and efficient diagnoses methods are developed for AS can we properly achieve later successes in treatment.

The review of literature uncovers a need for a universal system of detection, possibly beginning (as some suggested) directly in the medical community where early developmental checks are already customary for children. Currently, there are several methods by which professionals screen for AS, however; this variability contributes to the lack of consistency in diagnosis. This study intends to develop a comprehensive screening device, which outperforms the variability of options available. Through this implementation, the hope would be to create consistent screening tool that properly identifies children at various levels of risk for AS.

Overall, the goal is to better identify children with specific needs. As experts continue to deliberate over the appropriate form of intervention, the object is to first create a more efficient screening process. After all, intervention cannot happen until after the child has been identified as someone who has particular needs. For Asperger

syndrome in particular, the hope is to get these children the help they need as soon as possible. Again, the research message consistently seems to be- the faster, the better. The future direction of research will then be able to properly focus on intervention strategies.

Strengths of the Paper

This paper summarized the current research highlighting the need for early identification. The outcome of this review is the consolidation of a large body of information about early detection of Asperger syndrome, including procedures currently used to screen for autistic-like disorders.

Limitations of the Paper

Although every effort was made, not all possible sources were obtained. The most current available research was gathered; however, information in this field is changing rapidly. The current paper may become obsolete, due to the rapidly changing field, in the near future.

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