

UNDERSTANDING LAG TIME IN CHILDREN WITH AUTISM SPECTRUM  
DISORDERS

by

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Understanding Lag Time in Children with Autism Spectrum Disorders

Thesis directed by Professor M. Franci Crepeau-Hobson

### **ABSTRACT**

Early identification of children with Autism Spectrum Disorders (ASD) can lead to earlier access to evidence-based intervention programs and services. The purpose of the current study was to identify lag time experienced by children with ASD as well as factors that may increase or decrease lag time. Factors of interest included Autism Diagnostic Observation Schedule - Second Edition (ADOS-2) Comparison Scores, family history of mental health, behaviors of concern, access to special education services, referral sources, and parental education level. One hundred twenty children with ASD ages 2 to 14 were identified at a small, private clinic in a large city in the western United States and data were collected via a retrospective review of records. Results indicated that children with ASD identified for this study did not receive a diagnosis until 3.988 years after parents initially reported concerns. A significant positive correlation was found between access to special education and lag time. Implications for lag time and early identification of ASD are discussed.

The form and content of this abstract are approved. I recommend its publication.

Approved: M. Franci Crepeau-Hobson

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## CHAPTER I

### INTRODUCTION

#### **Problem and Significance**

Autism Spectrum Disorder (ASD) was discovered in 1943 by Kanner, defining the symptoms as “‘extreme autistic aloneness’, abnormal speech with echolalia, pronominal reversal, literalness, and inability to use language for communication; and monotonous, repetitive behaviors with an ‘anxiously obsessive desire for the maintenance of sameness’” (Wolff, 2004, p. 203). Factors influencing ASD have been hypothesized since its discovery, with attempts to link ASD to numerous childhood disorders and experiences, such as childhood schizophrenia, highly intelligent parents, refrigerator parents, and children with brain damage and intellectual disabilities (Wolff, 2004).

Asperger joined the discussion in 1944, describing four children whom he believed to have autistic psychopathy of childhood (Wolff, 2004). These children often had cognitive gifts in mathematics or sciences, but struggled with social and emotional functioning. Specifically, they lacked social reciprocity, had stereotypic behaviors, and exhibited restricted interests. Asperger noted that the condition could be recognized in early childhood and continued throughout the child’s lifetime (Wolff, 2004). Kanner’s and Asperger’s early definitions and noted symptoms of ASD have not changed much over time, as ASD is now defined as a neurodevelopmental disorder that affects the domains of social interaction, communication, and repetitive or stereotypic behavior (Newschaffer et al., 2007). It is also accepted that these symptoms begin to present before 3 years of age (Smith, 1999). These three social domains are found in the Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition (DSM-V) diagnosis criteria for ASD, which will be discussed in detail in the Literature Review below (American Psychological Association, 2013).

The Centers for Disease Control reports the prevalence of ASD to be 14.6 per 1,000 children, which equates to about 1 in 68 children presenting with ASD for the surveillance year of 2012 (Christensen et al., 2016). Although the prevalence for 2012 is very similar to the prevalence equated in 2010 (14.7 per 1,000, 1 in 68), ASD prevalence has increased greatly since the year 2000 when ASD had a prevalence of 6.7 per 1,000 children (about 1 in 150 children).

The undeniable increase in prevalence reinforces the need for research focusing on ASD and the need for early intervention for children with the disorder. Therefore, this research paper examines the lag time between parents' first concerns and their child's first ASD diagnosis with the following research questions:

1. What is the length of time between parent's initial concerns and the diagnosis of Autism Spectrum Disorder?
2. What is the relationship between symptom severities as measured by the Autism Diagnostic Observation Schedule - Second Edition (ADOS-2) Comparison Scores and length of time between initial concerns and diagnosis?
3. What factors are related to the amount of time between initial concerns and diagnosis?

This study aims to clarify the relationship between ADOS-2 Comparison Scores and time lag to diagnosis with the hypothesis that more severe symptomology will be related to less time lag between parents' initial concerns and a diagnosis of ASD. In addition, this paper aims to identify additional factors that are related to the amount of time between parents' initial concerns and ASD diagnosis. In this way resources, systems, and/or areas of communication that may foster shorter time frames might be identified so that children with ASD can receive much needed early intervention.

## CHAPTER II

### LITERATURE REVIEW

#### **Autism Spectrum Disorder**

Individuals with Autism Spectrum Disorder (ASD) struggle with social communication, comprehension and pragmatic language, repetitive behaviors, adaptive behaviors, and social reciprocity (Kroncke, Willard, & Huckabee, 2016). The Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition's (DSM-V; American Psychological Association [APA], 2013) diagnostic criteria for ASD include a number of social deficits. Specifically, the person must exhibit "persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following": (1) "Deficits in social-emotional reciprocity", (2) "Deficits in nonverbal communicative behaviors used for social interaction", and (3) "Deficits in developing, maintaining, and understanding relationships" (APA, 2013, p. 50). These three deficits make up the social communication impairment part of the diagnosis and can be specified using a severity rating of Level 1, 2, or 3. Level 1 represents "Requiring support", Level 2 represents "Requiring substantial support", and Level 3 represents "Requiring very substantial support".

The second set of diagnostic criteria for ASD found in the DSM-V includes "restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following": (1) "Stereotyped or repetitive motor movements, use of objects or speech", (2) "Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior", (3) "Highly restricted, fixated interests that are abnormal in intensity or focus", and (4) "Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment" (APA, 2013, p. 50). Restricted, repetitive patterns of



behavior can also be qualified using the same severity level rating as social communication impairment (Level 1, 2, or 3).

### **Prevalence of Autism Spectrum Disorder**

Autism is now the fastest growing developmental disorder, with an increase of 23% from 2006 to 2008 and an increase of 78% from 2002 to 2008 (Kroncke et al., 2016). The DSM-V recently combined Asperger Syndrome, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and Autism into one Autism Spectrum Disorder in 2013. This change may cause a slight increase in prevalence moving forward due to the inclusion of children who would have been diagnosed with Asperger Syndrome or PDD-NOS in ASD statistics. Regardless, statistics of ASD prevalence prior to 2013 are alarming.

### **Identification of Autism Spectrum Disorder**

Knowing that ASD affects social communication and behavior, assessment and identification of ASD relies on open-ended social interactions and observations. Although assessment of ASD can look much different than assessment of cognitive skills, diagnosis is still based in standardized assessments, such as the Autism Diagnostic Observation Schedule - Second Edition (ADOS-2; Lord et al., 2012) or Autism Diagnostic Interview - Revised (ADI-R; Rutter, LeCouteur, & Lord, 2003, 2008). Research surrounding the ADOS-2 is quite strong as Sappok et al. (2013) found the ADOS-2 to be a very sensitive measure, with 100% sensitivity for ASD and 85% sensitivity for autism.

### **Early Intervention**

Each individual diagnosed with autism generates approximately \$3.2 million in costs to society over the course of his or her lifetime, according to a report from the Archives of Pediatrics & Adolescent Medicine (“Autism Costs”, 2007). Thus, it is critical that individuals with ASD be identified and supported as early as possible. Studies have emphasized the

importance of early intervention for children with ASD since the 1980s (Newschaffer et al., 2007).

Research studies have repeatedly found that children with autism make major gains with early intervention (Smith, 1999). Corsello (2005) compared many programs such as the TEACCH Home Program (Ozonoff & Cathcart, 1998), Discrete Trial (Lovaas, 1987), Applied Behavior Analysis (Harris & Handleman, 2000), The Greenspan Model (Greenspan & Wieder, 1997), and The Denver Model (Rogers & Lewis, 1989) and concluded that children with ASD make greater gains in positive affect, pragmatic communication, and interpersonal interactions when they begin intervention programs at younger ages – ideally before the age of 4-5 years.

Based on research results, Rogers (1996) concluded that children with ASD benefit most from interventions that begin between ages 2 and 4 as they end up making far more progress than older children who receive the same interventions. Rogers also noted that children with ASD are able to make more rapid gains than young children with neurodevelopmental disorders, suggesting that there is a critical period for intervention with children with autism between the ages 2-4 (1996).

Wong et al. (2005) recently completed a comprehensive evidence-based practice review that identified twenty-seven practices as meeting their criteria for being evidence-based in the intervention of individuals with autism ages 0-22. The majority of research was conducted with children with autism ages 6-11, with preschool age (3-5) also having a large amount of research to draw from. These evidence-based practices primarily focused on communication, social interaction, challenging behaviors, play, school readiness skills, pre-academic/academic skills, and adaptive self-help skills, showing that early intervention in children with ASD has a wide-variety of evidence-based curriculum and interventions. Given

the evidence-based effectiveness of early intervention found in multiple studies, it is clear that early intervention for children with autism is crucial. With an increased understanding of lag time between initial parental concern and a diagnosis of ASD, children with autism are more likely to receive evidence-based interventions at a younger age.

### **Applied Behavior Analysis and Behavior Modification**

B.F. Skinner is credited with the creation of behavior modification and defines it in his 1974 book, *About Behaviorism*, as the philosophy of the science of human behavior (1974). Skinner discovered the principles of behavior in research involving pigeons and rats, believing that these principles were applicable to all species, including human beings (1953). Skinner then transitioned to verbal behavior, focusing on echoics, mands, tacts, and intraverbals; or reinforced bids for conversation (1957). Skinner's work provided the foundation for the development of Applied Behavior Analysis (ABA). Baer, Wolf, and Risley (1968) defined ABA as the direct application of the principles of behaviorism to the improvement of human behavior. Although ABA began with the aim of improving all human beings and human behaviors, a 2012 review of existing literature concludes that ABA has significantly narrowed its focus to persons with developmental disabilities, such as individuals with autism, fetal alcohol syndrome, and Down syndrome (Axelrod, McElrath, & Wine, 2012). Early intervention in the form of ABA as early as 22 months of age can help to improve intellectual functioning, language development, and adaptive behavior of children with ASD (Virués-Ortega, 2010).

### **Lag Time**

Despite encouragement of early identification by health care professionals, significant lag time between parental concerns about their child's development and/or behavior and age at which the child receives a diagnosis of autism is consistently reported in

literature (Wiggins, Baio, & Rice, 2006). Frith and Soares found that parental concern developed between 12 and 23 months of age, yet the children did not receive a professional diagnosis until 36 to 70 months of age (lag = 24 to 47 months; 1993). Howlin and Ashgarian's study reported similar findings by noting initial parental concerns at an average of 18 months of age and a receipt of a professional autism diagnosis coming at an average age of 66 months (lag = 48 months; 1999). Sivberg more recently found a delay of 20 to 60 months between parental concerns and professional diagnosis (2003). Wiggins et al. found that children with autism are not diagnosed, on average, until 13 months after an initial evaluation by a qualified professional (2006).

In Japan, Fujiwara, Okuyama, and Funahashi (2011) found an average lag time between parental concerns and first visit to a hospital for diagnosis and treatment of ASD to be 2.9 years. This study also examined factors that influenced time lag for children. They found the following to be risk factors that may increase lag time: younger age at first parental concern, living with younger siblings, problems in interacting with others or not attending school, parents' difficulties determining whom to consult, parents having visited the hospital via other institutions, longer commute times, and longer waiting times (Fujiwara et al., 2011). Fujiwara et al. also identified several protective factors for lag time: older age at first parental concern, living with father, and having developmental delays (2011). The gender of the child, socioeconomic status of the parents, and degree of impairment were not associated with lag time (Fujiwara et al., 2011). A subsequent study found a similar two-year difference between the earliest signs of ASD and mean age of diagnosis, reporting contributing factors such as time-consuming evaluations, cost of care, lack of providers, and a lack of comfort of primary care providers to diagnose autism (Gordon-Lipkin, Foster, & Peacock, 2016).

Collectively, research findings suggest that children with ASD are not receiving a professional diagnosis until 20 to 60 months after their parents initially report concerns. Put into perspective, these results suggest that it is possible for a 2-year-old child with ASD to not receive a diagnosis and subsequent intervention services until they are 4-7 years of age. Clearly, such a significant delay in the receipt of imperative early interventions is extremely costly and concerning due to subsequent need for therapy and support services and costs to society.

By linking ADOS-2 Comparison Scores to lag time, this study aims to identify those factors that may be related to time lag in children with autism. By understanding and identifying variables related to lag time in children with autism, future research can examine how identifying factors can be used to connect these children to needed resources and interventions at an earlier age. Specifically, this study will investigate the relationship between lag time and ADOS-2 Comparison Scores, family history of mental health, behaviors of concern, access to special education services, referral sources, and parental education level.

## CHAPTER III

### METHOD

The Colorado Multiple Institutional Review Board (COMIRB) approved this study for exemption on September 23, 2016.

#### **Participants**

Study participants were identified through a record review at a small, private clinic in a large city in the western United States. Records for child clients evaluated from January 1, 2014 until June 1, 2016 were reviewed. Inclusion criteria included: meeting the diagnostic criteria for ASD as defined by the DSM-IV or DSM-V, depending upon the date of the evaluation; completed ADOS-2 Module 1, 2, or 3 manuals; and completed intake information. Children with neurological disorders that present at birth, such as Cerebral Palsy, as well as ASD were not considered for the present study as parents' reported concerns might be related to Cerebral Palsy and not ASD. Additionally, adopted children and stepchildren were excluded from the study due to the potential delay in noted concerns. Participants with a preexisting diagnosis of ASD were considered for this study as long as the original evaluation date was presented, original ADOS-2 scores were reported, and first concerns were noted in the original intake packet. Diagnoses of Asperger Disorder, Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS), general ASD in the DSM-IV, or ASD in the DSM-V were included in the present analysis.

#### **Measures**

*Symptoms of Autism.* The Autism Diagnostic Observation Schedule - Second Edition (ADOS-2; Lord et al., 2012) is a semi-structured measure that clinicians use to assess a child's ability to play and communicate through naturalistic observation with the use of defined sets and activities and assessment criteria (Kroncke et al., 2016). In 2007, the ADOS

algorithms were revised using a sample of 1,139 participants aged 14 months to 16 years, creating the ADOS-2 (Lord et al., 2012). For this research project, ADOS-2 protocols were reviewed to record Comparison Scores. ADOS-2 Modules 1, 2, and 3 were included in this research as these modules provided a 1-10 ASD Comparison Score. Comparison Scores are less influenced by verbal language level, thus representing a severity metric as independent as possible from intellectual ability, language, and age (Esler et al., 2015). Comparison Scores collected ranged from 3-10, as scores of 1 or 2 on the ADOS-2 do not meet criteria for a diagnosis of ASD when taken into consideration with other data collected during the evaluation. ADOS-2 Toddler Module and Module 4 were excluded as they do not offer the Comparison Score statistic.

*Demographics.* Upon intake at the clinic, parents completed a Client Registration Form – Child/Minor and Client Questionnaire (CRF; see Appendix A & B; Kroncke et al., 2016). This form provided the following data: date of birth, age, gender, diagnoses and other conditions, ethnicity of client, languages spoken at home, mother’s highest level of education attained, father’s highest level of education attained, and with whom the child currently lives. Additionally, via this form, parents reported initial age at which first concerns were observed, referral agency or individual, family history (e.g., psychological/emotional problems, autism, speech concerns), behavioral issues (e.g., aggression, cruelty to animals, mood swings), and prior special education services.

## **Procedure**

The process of participant identification began with a review of evaluations. If the evaluation resulted in a diagnosis of ASD, the record was pulled and the CRF was reviewed. De-identified data were recorded into a password-protected server.

During the data collection process, files were pulled in alphabetical order and were first reviewed to see if a psychological evaluation report was present. If present, the next step was to determine if the record qualified for inclusion. If a record did indeed meet inclusion criteria, the record was reviewed and data were recorded.

Predictor variables that were categorical or ordinal in nature (i.e., 0 times, 1 time, 2 or 3 times, 4 or 5 times, 6 or more times) were either dichotomized using dummy variables of 1 for 0 times or 2 for 1 or more times or combined into three groups with dummy variables (e.g., 1 for low, 2 for moderate, 3 for high). For example, a binary categorical variable was created in which any family history of psychological or emotional difficulties, ASD, or speech difficulties was combined. A response of yes to any family history was coded as a 1 and no family history was coded as 2, creating the variable Family History Total. Behaviors of concern were similarly combined. However, subjects were split into three groups based upon the total behaviors of concern reported. These groups were Low Behaviors (0-5 behaviors), Moderate Behaviors (6-10 behaviors), and High Behaviors (11-15 behaviors). Parental education was coded similarly to behaviors of concern by using three groups, high school level (low), college level (moderate), and graduate level (high).

Referral sources were coded dichotomously, but were too numerous to include all in the regression analysis. Therefore, the three most common referral sources were chosen first (Doctor, School, and Insurance referrals). A fourth referral source (Self-referrals) was selected by the researcher, as subjects self-referred for evaluations leading to a diagnosis of ASD were considered most likely to have different lag time data.

### **Demographics**

Of all children diagnosed with ASD in the required date range, 120 cases ( $n = 120$ ) between the ages of 2 and 14 years of age were considered for the present analysis. The



participants in this study were 85% male (n = 102). The majority (80.7%; n = 96) of subjects identified as Caucasian, while 11.7% of subjects identified as Other or Multiple ethnicities (n = 14). Five percent of subjects identified as Hispanic ethnicity (n = 6), 1.7% identified as African-American ethnicity (n = 2), and 0.8% identified as Asian-Pacific (n = 1). Prior access to special education services was reported by 54.17% of subjects (n = 65).

Data were also collected relating to parental education level, indicating that 13.56% of mothers completed some portion of high school, 58.47% of mothers completed some portion of college, and 27.97% of mothers completed some portion of graduate school. Additionally, 17.09% of subjects' fathers completed some portion of high school, 49.49% of fathers completed some portion of college, and 29.06% of fathers completed some portion of graduate school.

Family history of psychological or emotional difficulties was reported by 55% of participating parents (n = 66), while family history of ASD was reported by 19.17% (n = 23). Family history of speech struggles was reported in 15.83% of cases (n = 19). Family History Total was found to contain 70.34% of subjects (n = 83).

Of the qualifying behavioral data (n = 116), it was found that 32.76% of subjects had 0-5 behaviors of concern (n = 38), 56.9% of subjects had 6-10 behaviors of concern (n = 66), and 10.34% of subjects had 11-15 behaviors of concern (n = 12).

The most common referral sources for subjects included in this evaluation are: Children's Hospital (17.5%; n = 21), Doctor/Pediatrician (16.7%; n = 20), School (14.2%; n = 17), and Psychologist/Psychiatrist (13.3%; n = 16). Other referral sources include: Other Therapists (10.0%; n = 12), Other (9.2%; n = 11), Insurance Companies (7.5%; n = 9), and Self-referrals (5.8%; n = 7). Demographics are presented in Table I.

## **Data Analyses**

Descriptive statistics were conducted to investigate Research Question 1: What is the length of time between parent's initial concerns and the diagnosis of Autism Spectrum Disorder? Lag time was calculated by subtracting the age at which the parent first reported concerns from the child's age at the time of their first psychological evaluation and then calculating the average for the subjects of this study.

Regression analyses were conducted to investigate Research Questions 2 and 3: What is the relationship between symptom severities as measured by the Autism Diagnostic Observation Schedule - Second Edition (ADOS-2) Comparison Scores and length of time between initial concerns and diagnosis? and What factors are related to the amount of time between initial concerns and diagnosis?

Specific pairwise comparisons were then conducted based upon significant factors found in the regression analyses to further clarify relationships.

Table I: *Demographics*

Variable	N	Minimum	Maximum	Mean	Std. Dev.
Report Age	120	2.583	14.833	7.811	3.179
First Concern	119	0.00	13.75	3.831	2.654
Lag Time	120	0.083	14.333	3.988	2.858
ADOS-2 Score	120	3	10	7.36	1.629
<i>Demographics</i>				<i>Percentage</i>	
Sex (Male=1)				85.0	
African-American				1.7	
Asian-Pacific				.8	
Caucasian				80.7	
Hispanic				5.0	
Other				11.8	
English Spoken at Home				98.3	
Spanish Spoken at Home				.9	
Arabic Spoken at Home				.9	
Access to Special Education Services				54.17	
Family History of Psychological/Emotional Difficulties				55.0	
Family History of Autism				19.17	
Family History of Speech Difficulties				15.83	
<b>Family History Total (n = 118)</b>				<b>70.34</b>	
Immunizations				90.83	
Aggressive Behaviors				64.17	
Bedwetting Behaviors				38.33	
Cruel Behaviors				8.33	
Destructive Behaviors				36.67	
Disobedient Behaviors				60.83	
Distractible Behaviors				79.17	
Eating Behaviors				45.0	
Hair Pulling Behaviors				13.33	
Masturbation Behaviors				8.33	
Mood Swing Behaviors				54.17	
Poor Concentration Behaviors				60.83	
Self Injurious Behaviors				30.83	
Poor Sleeping Behaviors				46.67	
Temper Behaviors				70.0	
Fear/Worry Behaviors				41.67	
<b>Total Behaviors (0-5)</b>				<b>32.76</b>	
<b>Total Behaviors (6-10)</b>				<b>56.90</b>	
<b>Total Behaviors (11-15)</b>				<b>10.34</b>	
<i>Referrals</i>					
School				14.2	
Doctor/Pediatrician				16.7	
Insurance Company				7.5	
Children's Hospital				17.5	
Psychologist/Psychiatrist				13.3	
Other Therapist (e.g. BCBA, OT, SLP)				10.0	
Programs/Clinics (e.g. DU, Aspire)				3.3	
Self-referred				5.8	
Other (e.g. friend of practice)				9.2	
Missing Data				2.5	
<i>Education</i>		<i>Mother (n = 118)</i>		<i>Father (n = 117)</i>	
10 <sup>th</sup> Grade			-		.9
11 <sup>th</sup> Grade			-		-
12 <sup>th</sup> Grade			13.6		16.2
<b>High School Total</b>			<b>13.56</b>		<b>17.09</b>
1 yr. College			6.8		4.3
2 yr. College			10.2		11.1
3 yr. College			3.4		3.4
4 yr. College			38.1		35.0
<b>College Total</b>			<b>58.47</b>		<b>49.49</b>
<b>Graduate School Total</b>			<b>27.97</b>		<b>29.06</b>

## CHAPTER IV

### RESULTS

#### **Lag Time Between Initial Concerns and Diagnosis of ASD**

Lag time was found to range from 1 month to 14 years, 4 months. The average lag time found in the data set was almost 4 years (3.988 years,  $SD = 1.63$ ); meaning subjects on average received a diagnosis of ASD nearly 4 years after the parents reported initial concerns.

#### **Relationship Between (ADOS-2) Comparison Scores and Lag Time**

A multiple regression analysis was conducted to answer the second research question: Do ADOS-2 Comparison Scores predict the length of time between initial concerns and diagnosis. When analyzing data for lag time, it was found that the data were positively skewed. Calculating the natural log of lag time accounted for the positive skew, creating a new variable. This new variable was then used in both regression analyses. Model 1 contains the ADOS-2 Comparison Score variable (ADOS). Model 2 includes the squared version of ADOS to determine if the relationship between ADOS and Lag Time was curvilinear. Assumptions of regression were checked and met. However, there were no significant results found in this regression analysis.

#### **Relationship Between Various Demographic Variables and Lag Time**

A second multiple regression analysis was performed to determine significance of the effect of demographic variables on lag time. The second regression analysis (Table II) included the following variables: access to special education services, total behavior, family history, maternal and paternal highest education completed, and various referral sources. Model 1 of the regression was comprised of access to special education services, Model 2 includes total behaviors, Model 3 includes family history, Model 4 adds education level,

while Model 5 includes referral sources. Assumptions of regression were checked and met. All five models of the second multiple regression were found to be significant at the  $p < .05$  level. In all nested models, access to special education was the only variable found to have a significant relationship with lag time even when all predictor variables were controlled for ( $\beta = .352, p < .01$ ).

After identifying access to special education as a significant predictor of lag time, a pairwise t-test was conducted to further analyze this relationship. The test confirmed that access to special education and lag time are significantly positively correlated ( $N = 119, r = .285, p < .01$ ), meaning that subjects of this study who had received special education services saw an increase in lag time compared to the overall subject population of this study.

Table II: Summary of Regression Analyses for Variables Predicting Lag Time ( $N = 107$ )

	Model 1		Model 2		Model 3		Model 4		Model 5						
	B	SEB	$\beta$	B	SEB	$\beta$	B	SEB	$\beta$	B	SEB	$\beta$			
(Constant) <sup>^</sup>	1.226***	.083		1.321***	.114		1.342***	.146		1.409***	.162		1.468***	.167	
SpEd Services	.373**	.113	.305	.367**	.113	.300	.360**	.118	.295	.353**	.119	.290	.352**	.119	.289
Total Behaviors (6-10)				-.162	.122	-.132	-.156	.125	-.127	-.164	.127	-.133	-.128	.127	-.104
Total Behaviors (11-15)				.011	.210	.005	.026	.220	.012	.026	.223	.012	.040	.221	.019
Family History							-.030	.133	-.022	-.044	.133	-.033	-.071	.132	-.053
Mother HS Educ										-.105	.189	-.060	-.076	.188	-.043
Mother Grad Educ										.117	.131	.086	.143	.131	.105
Father HS Educ										.037	.176	.021	.001	.176	.000
Father Grad Educ										-.246	.129	-.185	-.204	.129	-.154
School Referral													-.241	.178	-.133
Doctor Referral													-.284	.158	-.174
Insurance Referral													.157	.208	.072
Self-Referral													-.250	.249	-.094
$R^2$	.093			.111			.112			.154			.206		
F	10.896**			4.333*			3.232*			2.255*			2.055*		

**p < .05\*, p < .01\*\*, p < .001\*\*\***

Natural Log of Lag Time <sup>^</sup>

## CHAPTER V

### DISCUSSION

The purpose of the current study was to identify lag time between parents' first concerns and initial diagnosis of ASD, as well as to identify factors that may influence lag time. The children in this study received a diagnosis of ASD on average nearly four years after their parents first became concerned. The average lag time found in this study is consistent with that found in previous research where lag time ranged from 24 months to 60 months (e.g., Frith & Soares, 1993; Howlin & Ashgarain, 1999; Sivberg, 2003; Fukijawara et al., 2011; Gordon-Lipkin et al., 2016). This is a significant amount of time in which evidence-based early intervention strategies could be working to improve language, behavior, and social interaction skills.

The results of the present study indicated that there is no significant relationship between ADOS-2 Comparison Scores and lag time. Although it was hypothesized that more significant symptomatology would result in parents seeking professional assistance sooner, the insignificant findings of this current study correlate with Fujiwara et al.'s previous study in which degree of impairment was not associated with lag time (2011).

When analyzing the potential relationships between demographic factors and lag time, a significant, positive correlation was found between access to special education and lag time, regardless of the other variables controlled for. No other factors were found to significantly predict lag time. This was surprising given that previous research identified factors such as problems interacting with others and a lack of providers to increase lag time (Fujiwara et al., 2011; Gordon-Lipkin et al., 2016). However, given the nature of this record-review study, some of these factors could not be assessed in the present study. This study did

find a significant positive correlation between access to special education and lag time, a factor that has not been considered in previous literature.

The results of the present study beg the question as to why children who receive special education services experience longer lag time in ASD diagnosis. Bitterman, Daley, Misra, Carlson, and Markowitz (2008) give insight into special education services of children with ASD, finding that parents of children with ASD took an average of 76.9 days to find services while parents of children with other disabilities took an average of 83.8 days. Bitterman et al. (2008) also found that parents of children with ASD reported increased effort to receive services when compared to parents of children with other disabilities. Children with ASD received significantly more services (5.4 different types of services) than children with other disabilities (3.5 different types of services; Bitterman et al., 2008), with speech and language therapy being the most common service received by children with ASD in preschool, elementary, and secondary education (Wei, Wagner, Christiano, Shattuck, & Yu, 2014). Finally, Bitterman et al. found parental satisfaction related to the quality of services received to be 86.8% satisfaction for parents of children with ASD (compared with 90.1% satisfaction for parents of children with other disabilities) with the overwhelming majority of parents of children with ASD reporting being satisfied or very satisfied with the program, the teachers, and the services received (2008). The findings of Bitterman et al. and Wei et al. suggest that the correlation between lag time and access to special education found in this study can be explained in part by satisfactory services received in the school setting.

Furthermore, Charman, Howlin, Berry, and Prince (2004) found that children with ASD made more rapid developmental progress in elementary school than they had in preschool in the areas of communication, daily living skills, and socialization over an 11-month period. Specifically, the children gained 10 age-equivalent months in communication



and 9 age-equivalent months in daily living skills and socialization (Charman et al., 2004). Charman et al. reported that autism symptom severity did not change over this time period (2004). Although this rate of development is still below the development of same-aged peers, it could account for some of the associated correlation between special education and lag time found in this study as increased development may cause parents to pause in pursuing medical diagnoses or services outside of the school setting.

Future studies should continue to focus on the impact of various factors on lag time. In order to further assess the relationship between special education services and lag time, a qualitative study using surveys and parent interviews is suggested. Parent input is crucial in identifying whether the positive correlation between special education and lag time is due to positive factors such as appropriate developmental progress and parental satisfaction or negative factors such as difficulties determining whom to consult or a lack of providers (Charman et al., 2004; Bitterman et al., 2008; Fujiwara et al., 2011; Lipkin-Gordon et al., 2016).

### **Limitations**

While the results from this study add to the literature, there are several limitations that should be noted. First and foremost, the small data set ( $n = 120$ ) limited the scope of this research study in terms of including all factors in the regression analyses. Additionally, there is a noticeable lack of diversity in the data used for this study. With 80.7% ( $n = 96$ ) of subjects identifying as Caucasian and 98.3% ( $n = 115$ ) of subjects identifying as English-speaking, the generalizability of this study to other groups is limited. Similarly, socioeconomic status was not considered in the data used for this study, as it was not collected.

Another limitation relates to the data collection process itself. Since data were collected via a records review, no interview or follow-up data could be collected. Such data could supply important information about the psychological evaluation process and the various routes parents take to receive a diagnosis for their child. Furthermore, records reviewed for this study were evaluated from January 1, 2014 until June 1, 2016, as this was when the most recent and most comprehensive intake questionnaires were implemented. This caused a large amount of data to be discarded due to variable and inconsistent intake questionnaire data.

Finally, this study simply identified factors that may potentially be related to lag time. It does not answer any questions related to cause and effect and why such factors may or may not impact lag time.

## **Conclusion**

The tremendous increase in ASD prevalence since the year 2000 continues to support the need for research of ASDs (Christensen et al., 2016; Kroncke et al., 2016). This need is further supported by research that finds the importance of early intervention in children with ASD. One such piece related to early intervention in children with ASD is time lag between first parental concern and first diagnosis of ASD. Therefore, the purpose of this current study was to identify lag time experienced by children with ASD as well as factors that may increase or decrease lag time.

Children who had accessed special education services experienced longer lag time between parents' first concern and a diagnosis of ASD. Continuing research utilizing parent surveys and interviews is needed to further clarify this relationship. It should be noted that this relationship might change given the addition of school-identified autism to special education labels, further warranting continuing research. Factors influencing lag or wait time,

is a relatively new topic in research surrounding ASD. Therefore, this study is simply a piece of the puzzle as researchers continue to examine lag time in children with ASD in hopes of connecting these children to evidence-based interventions at younger ages.

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## APPENDIX A

## Client Registration Form – Child/Minor

<p><b>Date Completed:</b> _____</p> <p><b>Client Legal Name (Last, First, MI):</b> _____</p> <p><b>Physical Street Address:</b> _____</p> <p><b>City:</b> _____ <b>State:</b> _____ <b>Zip Code:</b> _____</p> <p><b>Mailing Address (if different):</b> _____</p> <p><b>Date of Birth:</b> _____ <b>Age:</b> _____ <b>Sex:</b> _____</p> <p><b>Social Security Number:</b> _____</p> <p><b>School:</b> _____ <b>Grade:</b> _____</p> <p><b>Diagnosis:</b> _____</p> <p><b>Other Conditions:</b> _____</p>
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<p><b>Ethnicity of Client</b> (check all that apply):</p> <p>African-American _____ Asian-Pacific _____ Caucasian _____ Hispanic _____ Other _____</p> <p><b>Language(s) spoken at home:</b> _____</p> <p><b>Religious/Spiritual/Cultural Beliefs:</b> _____</p>
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<p><b>Mother/Legal Guardian Name:</b> _____</p> <p><b>Mother/Legal Guardian Date of Birth:</b> _____</p> <p><b>Relationship to client</b> (<i>please check one</i>): Biological _____ Adoptive _____ Step _____ Foster _____</p> <p><b>Address:</b> _____</p> <p><b>Phone:</b> Home _____ Work _____ Cell _____</p> <p><b>Email:</b> _____</p> <p><b>Occupation:</b> _____</p> <p><b>Highest Level of Education Attained</b> (please circle):</p> <p>High School: 9 10 11 12      College: 1 2 3 4      Graduate School</p>
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<p><b>Employer Name:</b></p> <p>_____</p> <p><b>Employer's Address:</b></p> <p>_____</p> <p><b>Employer's Phone:</b> _____</p> <p><b>Father/Legal Guardian Name:</b></p> <p>_____</p> <p><b>Father/Legal Guardian Date of Birth:</b> _____</p> <p><b>Relationship to client</b> (<i>please check one</i>): Biological ___ Adoptive ___ Step ___ Foster ___</p> <p><b>Address:</b></p> <p>_____</p> <p><b>Phone:</b> Home _____ Work _____</p> <p>Cell _____</p> <p><b>Email:</b></p> <p>_____</p> <p><b>Occupation:</b> _____</p> <p><b>Highest Level of Education Attained</b> (<i>please circle</i>):</p> <p>High School: 9 10 11 12      College: 1 2 3 4      Graduate School</p> <p><b>Employer Name:</b></p> <p>_____</p> <p><b>Employer's Address:</b></p> <p>_____</p> <p><b>Employer's Phone:</b> _____</p>
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<p><b>Parent's Marital Status</b> (<i>check</i>): Married ___ Separated ___ Divorced ___ Single ___ Widowed ___</p> <p><b>Child Lives with</b> (<i>check all that apply</i>): Father ___ Mother ___ Other ___ Specify _____</p>
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<p><b>Client's Siblings:</b></p> <p>Name _____ Age _____ Gender _____</p> <p>Name _____ Age _____ Gender _____</p> <p>Name _____ Age _____ Gender _____</p> <p>Name _____ Age _____ Gender _____</p>
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<p><b>Client's Primary Care Physician:</b></p> <p><b>Name:</b></p> <p>_____</p> <p><b>Clinic/Company Practice Name:</b></p> <p>_____</p>
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<p><b>Address:</b></p> <hr/>
<p><b>Phone:</b> _____ <b>Fax:</b></p> <hr/>
<p><b>Email:</b></p> <hr/>
<p>Would you like Emerge to exchange clinical information with your child's PCP or other mental health/behavioral/medical provider? (please check one)    Yes _____ No _____ N/A _____</p>
<p><b>***If yes, please complete the included Release of Information form for each provider***</b></p>

**APPENDIX B**

**Client Questionnaire**

Client Name: \_\_\_\_\_ Date: \_\_\_\_\_

**PART 1 - Concerns and Strengths**

**What specific concerns do you have about your child?**

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**When did you first develop these concerns?**

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**Whom have you seen previously about your concerns and what were you told about your child?**

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**What are your child's interests and strengths? What does he/she like to do?**

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What questions would you like answered during the evaluation (if applicable)?

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What agency or individual referred you to Emerge?

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

## **PART 2 - Family History**

Is there any history of the following on either side of the child's biologic parents' families? If yes, please indicate with and "X" on Father's or Mother's side or other blood relative (please indicate who).

<b>Description</b>	<b>Father</b>	<b>Mother</b>	<b>Other Blood Relative:</b>
Psychological/Emotional Problems			
Intellectual Disability			
Learning Disabilities			
Birth Defects			
Seizures/Convulsions			
Tuberculosis			
Neurological Disease			
Diabetes			
Cancer			
Allergies/Asthma			
Gland Disorder/Thyroid			
Hearing Impairments			
Vision Impairments			
Hyperactivity			
Miscarriages			
Slow Development			
Autism			
Fragile X			
Speech Problems			
Other:			
Other:			

Please explain any conditions present on either side of the family.

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## **PART 3 - Pregnancy and Birth History**

Please list all pregnancies and miscarriages of child's biological mother (in chronological order).

Birth Date	Birth Weight	Health or Development

Please describe anything unusual or exceptional about the pregnancy and/or birth of the client.

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The baby was born: Early \_\_\_ Late \_\_\_ On Time \_\_\_ Number of Weeks \_\_\_\_\_

The baby was born by: Normal Vertex (head down) \_\_\_ Breech \_\_\_ C-section \_\_\_

Baby's birth weight: \_\_\_\_\_ lbs \_\_\_\_\_ oz Length: \_\_\_\_\_ inches Apgar Score: \_\_\_\_\_

Are biologic parents related to one another by blood: No \_\_\_ Yes \_\_\_ : How:

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Please check any of the following if present during pregnancy or birth.

<input type="checkbox"/> Excessive Bleeding	<input type="checkbox"/> Fever	<input type="checkbox"/> Rash
<input type="checkbox"/> Prescription Drugs	<input type="checkbox"/> Toxemia	<input type="checkbox"/> Poor Weight Gain
<input type="checkbox"/> Illicit/Street Drugs	<input type="checkbox"/> Cigarettes	<input type="checkbox"/> Narcotics
<input type="checkbox"/> Alcohol	<input type="checkbox"/> Supplemental Oxygen	<input type="checkbox"/> Illnesses

Please check any of the following if present during newborn period.

<input type="checkbox"/> Jaundice	<input type="checkbox"/> Feeding Difficulties	<input type="checkbox"/> Suspicion of Infection
<input type="checkbox"/> Poor Temperature Control	<input type="checkbox"/> Poor Activity	<input type="checkbox"/> Other

#### **PART 4 - Nutritional History**

Breast Fed: Yes \_\_\_ No \_\_\_ For how long? \_\_\_\_\_ months

Formula Fed: Yes \_\_\_ No \_\_\_ Name of Formula: \_\_\_\_\_

When were foods added: \_\_\_\_\_

When weaned to a cup: \_\_\_\_\_

Weight at one year: \_\_\_\_\_ lbs \_\_\_\_\_ oz

Do you have concerns about your child's current eating habits/diet?

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### **PART 5 - Development History**

**Developmental Milestones: Write down the age when your child first did each of the following. Write "NA" if your child has not done it yet. Write "DK" if you don't know/remember.**

Smiled		Held Head Erect		Separated Easily from Mother	
Imitated Sounds		Rolled Over		Ate Unaided with Spoon	
Said "Mama" or "Dada"		Sat Alone		Knew Colors	
Said other single words		Crawled		Started Counting	
Followed simple directions		Walked Alone		Recited Total Alphabet	
Said 2 to 3 word phrases		Rode Tricycle		Read Words	

**In general, did you feel that your child developed:** Quickly\_\_\_\_ Typically\_\_\_\_ Slowly\_\_\_\_

**Temperament: Please comment on the following behaviors for your child as an infant and as a toddler.**

- How active is your child?

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- How well does your child deal with transition and change?

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- How well does your child respond to new places, people and things?

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- What is your child's basic mood? Happy\_\_\_\_ Sad\_\_\_\_ Angry\_\_\_\_ Quiet\_\_\_\_  
Other\_\_\_\_\_

- Is your child predictable in patterns of sleep, appetite, etc?

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## **PART 6 - Medical History**

Please indicate if the following are relevant to your child currently or in the past. Check "Yes" or "No". If yes, please explain. You may use the back of the form if you require additional writing space.

<b>Description</b>	<b>Yes</b>	<b>No</b>	<b>Explanation/Specify/Treating Doctor's Name</b>
Abdominal Pain/Bowel Issues			
Allergies			
Anemia			
Birth Defects			
Blood Disorders			
Concussion/Head Injury			
Dental Problems			
Drooling			
Ear Infections			
Eating Issues/Gags/Chokes			
Headaches			
Hearing Loss			
Heart Condition			
Hormone Problems			
Ingestion of Poisons			
Joint or Bone Problems			
Lung/Breathing Problems			
Seizures or Convulsions			
Significant Accidents			
Skin Disease			
Tics or Repetitive Behavior			
Urinary Problems/Infections			
Other Medical Concerns			

**Child's Current Weight:** \_\_\_\_\_ lbs \_\_\_\_\_ oz      **Child's Current Height:** \_\_\_\_\_ ft \_\_\_\_\_ in

**Are your child's immunizations up to date?** Yes \_\_\_\_\_ No \_\_\_\_\_

**List any hospitalizations and operations of the client. Please include approximate dates:**

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**List all medications that your child is currently taking.**

Medication Name	Dosage	Frequency	Prescribing Doctor Name

Please indicate if the following actions are relevant to your child currently or in the past. Please check "Yes" or "No" and if yes, please explain/specify. You may use the back of the form if you require additional writing space.

Description	Yes	No	Explanation/Specify
Aggression			
Bedwetting			
Breath Holding			
Cruelty of Animals			
Destructiveness			
Difficulty Toilet Training			
Disobedience			
Distractibility			
Eating Problems			
Hair Pulling			
Masturbation			
Mood Swings			
Nail Biting			
Poor Concentration			
Self-injurious Behavior (i.e.: head banging)			
Sleep Problems			
Temper Tantrums			
Thumb Sucking			
Unusual Fear			

Any other behavior issues that you would like to mention or explain?

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**Does your child do any of the following? Please check “Yes” or “No” and explain if necessary.**

<b>Description</b>	<b>Yes</b>	<b>No</b>	<b>Explanation</b>
Get along with other children			
Become easily upset or frustrated			
Become angry or destructive easily			
Become overactive			
Prefer to be alone			
Misbehave frequently			
Have difficulty sitting still			
Have any problem with awkwardness or clumsiness			
Listen well			
Follow spoken directions			

**Please list all of your child's current and previous mental/behavioral health providers. Please also include any past developmental evaluations or testing your child has had.**

<b>Provider Name</b>	<b>Service Provided</b>	<b>Approximate Dates</b>	<b>Outcome and/or</b>

**How do you discipline your child? Please give an example.**

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### **PART 7 - Educational Profile**

Please indicate the schools your child has attended in chronological order from current to oldest.

School Name	Grade/Level	Dates Attended

Has your child ever received special education services? Please explain.

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Describe any current school programs.

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Does your child or family utilize any other community resources (support groups, social services, etc)? Please list.

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**Please tell us what you consider to be important goals for your child in the following areas:**

Communication:

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Social Skills and Relationship Development:

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Sensory Integration and Motor Skills Development:

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Structured Learning, Pre-Academics and Academic Skills:

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**Is your child or family currently involved in any legal issues? If yes, please explain.**

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**As a family, we'd like to be able to...**

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**Places in the community that we enjoy are...**

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**Emerge, P.C. can help our family by....**

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**If you feel that there is additional information you would like to provide that would help us to know you or your child better, please include that information below.**

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