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Lag Time between Parental First Concerns about Development and Entry into Early Intervention: Impact of Child/Family Factors, First Concerns, and Symptom Presentation

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LAG TIME BETWEEN PARENTAL FIRST CONCERNS ABOUT DEVELOPMENT AND ENTRY INTO EARLY INTERVENTION: IMPACT OF CHILD/FAMILY FACTORS, FIRST CONCERNS, AND SYMPTOM PRESENTATION

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ABSTRACT

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that impacts an individual's ability to relate to and communicate with others. Although children often do not receive a diagnosis until age 4-5 years (Centers for Disease Control and Prevention, 2014), parents typically recognize developmental problems by age 2 years (Chawarska et al., 2007), and often in the first year of life (Kishore & Basu, 2011). However, these early concerns do not always translate into appropriate or timely steps to access care. Few studies have examined factors relating to the time lag that exists between early concerns and action. Because early intervention for ASD is critical for best outcomes, it is important to understand factors that can delay access to treatment. The current study included 4,215 toddlers between the ages of 16-37 months who were evaluated for an IDEA, Part C early intervention program in Louisiana. It closely examined child and family factors (i.e., the age of the child when parents first note concerns, gender, ethnicity, birth order, presence of a family member with ASD), the nature of early parental concerns, and symptom presentation to determine how these factors impact the time lag between parental first concern and entry into an early intervention program. Ethnicity was found to be a significant predictor of lag time such that minority families experienced a longer lag. The disparity was present across all functioning levels, although the difference was most pronounced for toddlers with functional impairments. Longer lags when parents reported general rather than specific concerns about their child's development were also noted. Additional findings, their implications, and future directions for research relating to lag time were discussed.

CHAPTER 1: INTRODUCTION

Autism Spectrum Disorder (ASD) is a life-long neurodevelopmental disorder with an onset very early in development. Core symptoms include social and communication deficits as well as the presence of repetitive behavior or restricted interests. In addition to the core symptoms, between 25.8 – 58.5% of individuals with ASD also meet criteria for a diagnosis of Intellectual Disability (ID), suggesting varying levels of cognitive impairment. In those who meet strict criteria for Autistic Disorder, the prevalence of ID is higher, 66-70% (Goin-Kochel, Peters, & Treadwell-Deering, 2008). Challenging behavior (e.g., aggression toward others, self-injury, tantrum behavior) and difficulty with adaptive skills (e.g., sleep, toileting, eating) are also commonly seen in individuals with ASD, although these behaviors are not diagnostic features (Bodfish, Symons, Parker, & Lewis, 2000; Murphy, Healy, & Leader, 2009). ASD was previously called Pervasive Developmental Disorder (PDD), suggesting that developmental and behavioral problems span multiple areas and result in significant impairment with daily functioning across areas. Due to the serious nature of ASD and the poor outcomes without treatment, appropriate and timely intervention is important.

Although symptoms of ASD are present throughout the lifetime, amelioration of symptoms and growth across domains of development is possible with appropriate treatment. Evidence-based intervention includes the use of Early and Intensive Behavioral Intervention (EIBI) using strategies consistent with Applied Behavior Analysis (ABA). Treatment is comprehensive, meaning goals address multiple areas of functioning to improve skills such as language, social skills, adaptive functioning, academics, as well as to decrease the frequency and intensity of challenging behavior. Intensive treatment includes up to 40 hours per week of 1:1 intervention. For best outcomes, early intervention is essential; researchers suggest two or more years of EIBI beginning by age 3 years, or even as early as age 2 years (Hoyson, Jamieson, &

Strain, 1984; McEachin, Smith, & Lovaas, 1993; Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011; Rogers & Lewis, 1989; Sheinkopf & Siegel, 1998).

The age when an individual with ASD is diagnosed varies widely. Children can be diagnosed as young as age 2 years, although most children with ASD are not diagnosed until age 4-5 years (Centers for Disease Control and Prevention [CDC], 2014). Furthermore, with milder presentations (including those previously diagnosed with Asperger's Disorder) the average age at the time of diagnosis has been found to be as old as 11 years (Howlin & Asgharian, 1999). Factors that may influence age of diagnosis include symptom severity, minority status, and low socioeconomic status (Howlin & Asgharian, 1999; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Mandell, Novak, & Zubritsky, 2005; Wiggins, Baio, & Rice, 2006). Often, a formal diagnosis is required before insurance companies will cover the cost of treatment.

When a child has ASD, parents are often aware of developmental problems very early in life. Researchers indicate that first concerns arise between age 13 months (Fombonne, 1999) and age 19 months (Howlin & Moore, 1997); however, many parents report concerns before their child's first birthday (Kishore & Basu, 2011). The most commonly reported area of first concern is related to language development or speech (DeGiacomo & Fombonne, 1998; Howlin & Moore, 1997; Kozlowski, Matson, Horovitz, Worley, & Neal, 2011; Meek, Robinson, & Jahromi, 2012). Social problems or the presence of challenging behavior are also commonly reported by parents as an area of first concern (DeGiacomo & Fombonne, 1998; Guinchat et al., 2012; Kozlowski et al., 2011). However, these first concerns do not always prompt immediate action.

It is clear that early intervention is critical for best outcomes. As such, early identification is imperative. Parents are often the first to note delays in development; thus, parental recognition

of developmental concerns is the first step to appropriate treatment. Subsequent to initial parental concern are efforts to have their child identified as delayed and enter into treatment. With many barriers to appropriate care (e.g., wait lists, costly treatment, high-intensity intervention, geographic availability of services, social stigma related to diagnosis, denial of problems), delay based on other factors including child and family factors must be identified and addressed. It is known that there is a lag between the time that a parent first becomes concerned and when a child receives care. What is not known, however, is what factors may impact the time from concern to action so that they may be addressed. The aim of this study was to examine factors impacting this lag in order to better facilitate early and appropriate intervention for all young children with ASD.

CHAPTER 2: HISTORY OF AUTISM SPECTRUM DISORDER (ASD)

Although "autism" is now a household word, and many people know someone with the disorder, it was not long ago when awareness about ASD was lacking. The lack of awareness contributed to an inaccurate diagnosis rate for many years. Autism has always been diagnosed based on clinical presentation as there are no definitive biological markers; thus, diagnostic criteria and awareness of symptomology are imperative for accurate diagnosis and have an impact on prevalence rates.

Early ASD Researchers

The word "autism" or "autistic thinking" was first used in 1913 by Eugen Bleuler, a Swiss psychiatrist. He used the term to describe the turning away from the external world manifested by individuals with schizophrenia who appear to be focused on the self, withdrawn, or, in severe cases, living in a dream world. In 1943, Leo Kanner, a physician practicing at the Children's Psychiatric Service of the Johns Hopkins Hospital in Baltimore, Maryland, described a group of individuals with an "autistic disturbance" who were socially avoidant but who did not meet criteria for schizophrenia. With a group of 11 children (8 male, 3 female) observed between the ages of 2 and 11 years, Kanner described an affective disorder with onset early in infancy, distinct from schizophrenia, with a cluster of symptoms typified by deficits in social communication (Kanner, 1943). The timing of symptom onset was suggestive of a disorder that is neurodevelopmental in nature rather than acquired after a period of typical development, as is the case for schizophrenia. Although Kanner's autism qualified as a new and rare disorder, Kanner suggested that previous misdiagnoses up until that point may have masked a problem that was not as unusual as it first appeared. Symptoms were described as an inability to relate to people and situations and a lack of social awareness (not a loss of skill as seen in individuals

with schizophrenia; rather, a failure to develop social skills or lack of social instinct). Other primary characteristics of the disorder included a lack of language to communicate, insistence on sameness, preoccupation with objects over people, eating difficulty, fear of loud noises and moving objects, and good cognitive potential.

Over the next several years, Kanner continued to study children with autistic features and described the primary problem evinced by all the children as the lack of ability to relate to others starting from infancy. He described behavior common to these children including the inability in infancy to react in an anticipatory manner when an adult approached them to pick them up, the misuse of personal pronouns, the use of echolalia or delayed echolalia, insistence on sameness, and an overall preference for objects over people (Kanner, 1944). By 1951, Kanner had begun to refer to the disorder as early infantile autism. He then listed the diagnostic features as including social withdrawal, obsessive insistence on sameness, preference for objects rather than people, intact intelligence, and language/communication impairments. Although Kanner initially described the disorder as occurring from birth, he later expanded this criterion to include children who regressed after a period of normal development at approximately age 18-20 months (Kanner & Eisenberg, 1957).

Concurrent with Kanner's work, Hans Asperger, a doctoral student in Austria, published a thesis entitled "Autistic Psychopathy in Childhood" in 1944 which was translated into English in 1991 by Uta Frith. Asperger described four children with a similar behavioral presentation as those described by Kanner, including deficits in social skills and the presence of stereotypic movements. Interestingly, the name he also chose for them was "autism." The children described by Asperger were different from those described by Kanner in that they demonstrated typical early development of language; however, their verbal communication resembled that of an adult

or “little professors” so remained remarkable. Also, the social use of the language was odd, being described as one-sided and containing preoccupations of certain topics (Klin, McPartland, & Volkmar, 2005). Autism, as described by Kanner, is now colloquially considered more “classic” autism, whereas Asperger’s Disorder, nomenclature used in later versions of the Diagnostic and Statistical Manual (DSM) but dropped in the fifth edition, is often characterized as a type of “high functioning” autism when ID is not present. The differences in symptom severity are characteristic of the current conceptualization of a dimensional approach to understanding the autism spectrum.

Because of the use of the term “autistic,” because the development of social withdrawal is a trait also seen in those with schizophrenia, and because the disorder described by Kanner and Asperger was not added to diagnostic manuals to clarify symptomology, there continued to be diagnostic confusion related to schizophrenia and autism until the early 1970s. Although there are striking differences between the two disorders, there were frequent misdiagnoses and a collapse of autism into the understanding of schizophrenia, which was also continuing to develop (Rutter, 1978).

As the disorder became more well-known, a dramatic increase in prevalence was noted. Kanner (1965) postulated that the explosion of autism diagnoses resulted from previous misdiagnoses of children with mental deficiencies and odd behavior. Despite the increase in recognition of the disorder at the time, diagnostic confusion remained due to a general climate that focused on treatment over assessment. Because all disorders of childhood (e.g., autism, schizophrenia, “feeblemindedness”) were thought to be caused by poor mother-infant bonding, differential diagnoses were not considered to be important (Rutter, 1968). As a result, researchers lumped all of the childhood disorders under the term “atypical development.”

Kanner was instrumental in offering early diagnostic criteria for autism as described above. In the late 1960s and throughout the 1970s, Michael Rutter of the Institute of Psychiatry in London, England, was another researcher who was critical to the development of formal diagnostic criteria. He described three core deficits in those with autism including social withdrawal, speech and language problems, and ritualistic/compulsive behavior which became the basis for later conceptualizations of the disorder as included in diagnostic manuals (Rutter, 1968; 1972; 1978).

Inclusion of ASD in Diagnostic Manuals

Prior to inclusion of ASD in diagnostic manuals, individuals with symptoms of autism were diagnosed with disorders such as infantile psychosis, schizophrenia, disintegrative psychosis (e.g., childhood disintegrative disorder), other psychoses, or mental retardation (Rutter et al., 1969). Misinformation about the disorder continued into the 1980s. Autism was not added to one of the two major classification systems until 1967, when the International Classification of Diseases (ICD), published by the World Health Organization (WHO), included a category for autism in its eighth edition. However, at that time, infantile autism was classified as a subgroup of schizophrenia (Ousley & Cermak, 2014). In 1977, ICD-9 was published, and infantile autism was classified as a type of childhood psychosis (Ousley & Cermak, 2014). The first two editions of the Diagnostic and Statistical Manual (DSM), published by the American Psychiatric Association, in 1952 and 1968 did not contain a category for autism.

Autism was finally included in the third edition of the DSM, published in 1980, at which time the category of PDD was added (APA, 1980). The inclusion marked the first time autism was given its own category and not designated as a psychotic disorder. In the third edition of the DSM, PDD was divided into two major categories including Infantile Autism and Childhood

Onset PDD. The main difference between the two disorders was the age of onset; however, this may not have reflected a true difference in presentation, rather, a difference in when symptoms were recognized. In a study by Volkmar, Stier, and Cohen (1985), 129 patients were studied with only five cases of apparent childhood onset. The behavioral presentation was indistinguishable between groups. Revisions to the DSM-III were completed in 1987 at which time Infantile Autism was renamed Autistic Disorder and the categories of Childhood Disintegrative Disorder and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) were added (APA, 1987). The WHO's ICD-10, published in 1992, and the DSM-IV, published by the APA in 1994 with text revisions published in 2000, contained very similar criteria and categories. Both included a diagnosis of Asperger's disorder/syndrome as well as a category for PDDs that did not meet full criteria for a diagnosis of autism (e.g., "not otherwise specified"). The DSM-5, published in 2013, combined the diagnoses of autistic disorder, Asperger's disorder, and PDD-NOS into a single, dimensional category, ASD, which has more rigorous diagnostic criteria and which describes two core features including social-communication/social interaction deficits and the presence of restricted and repetitive behavior (APA).

Core Features of ASD

Core diagnostic symptoms of ASD include deficits in social communication and excesses in ritualistic and repetitive behavior. Depending on which diagnostic manual is used, social skills may be outlined separately from communication skills. Understandably, these skills are related; however, social communication is a broad category and certainly can be broken down into components such as nonverbal and verbal skills or those skills that are more play or relationship based and those skills that are more language based. For the purpose of explaining deficits, social skills will be outlined as distinct from communication skills in this paper.

Deficits in Socialization

Social deficits are commonly described as the hallmark feature of ASD (Rutter, 1968; Sevin, Knight, & Braud, 2007). Social skills include behaviors such as eye-to-eye gaze, social smiling, joint attention, shared enjoyment, imitation, pretend play skills as well as behaviors that denote an understanding of theory of mind and the ability to empathize with others. Such skills are necessary for establishing and maintaining friendships and other social relationships. In infancy, deficits may be noted as early as age 6 months (Maestro et al., 2005; Muratori, Apicella, Muratori, & Maestro, 2011). Kanner's description of the failure of an infant to develop an anticipatory body posture when a caregiver moved to pick them up as well as what he described as the preference of objects over people would be examples of early markers of social impairment. Children with ASD are less likely than their typical peers to respond to their name (Osterling & Dawson, 1994), are less likely to point to indicate interest or direct attention (Osório, Martins, Meins, Martins, & Soares, 2011; Suzuki, 2011), have difficulty with imitation (Williams, Whiten, & Singh, 2004), have difficulty with imaginative play (Rutter & Bartak, 1971), and have difficulty understanding the affective states of others as well as expressing themselves through their affect (Muratori et al., 2011). As is true for all symptoms of ASD, heterogeneity exists around the severity of presentation (Hattier & Matson, 2012). A lack of basic social skills/attunement to others may be present, or, in the case of less impaired individuals, a more subtle deficit in the ability to read social cues may exist. Because social demands increase with age, deficits may become more apparent as the child ages, especially for those with less severe symptoms.

Deficits in Communication

Language development, including speech problems, is the area that most parents become concerned about first in those with ASD (Kozlowski et al., 2011). Receptive and/or expressive language impairments are often noted early in development. Receptive language, or what is understood, is demonstrated by the ability to point to items (e.g., "show me the ball") or to follow single and multi-step directions. Expressive language, what is said, includes a child's use of words, phrases, and sentences to communicate. When a general, expressive language delay is present, children without ASD can compensate to some degree with the use of nonverbal communication including the use of gestures, body language, and facial expression directed to others as a means of communication. However, individuals with ASD who have a language delay do not compensate adequately; in fact, even those individuals with ASD who do not evince a clinically significant language delay early in development have notable deficits in nonverbal communication.

Heterogeneity in symptom presentation in the area of communication is, again, large. At the severe end of the spectrum, an absence of speech is present throughout the lifespan (Dawson & Murias, 2009; Rutter, 1978). Less severe symptomatology includes pronoun reversals, the use of immediate or delayed echolalia, and difficulty with figurative language (Bertoglio & Hendron, 2009; Eveloff, 1960). Also common are problems with the use of inflection and intonation. In 20-37 percent of cases of ASD, there is some amount of regression reported between ages of 1-3 years (Barger, Campbell, & McDonough, 2013; Goin-Kochel, Esler, Kanne, & Hus, 2014; Matson & Kozlowski, 2010), and this is often in the area of communication.

Excesses in Restricted, Repetitive, and Stereotyped Behavior

The final area of core difficulty concerns the unusual behavioral presentation. Restricted and repetitive behavior is a broad area that encapsulates the rigidity of individuals with ASD that makes the tolerating of change and certain aspects of the social world very difficult. A lower order type of behavior that falls into this category includes the presence of repetitive motor behavior such as stereotypies. Examples include repetitive hand flapping, finger flicking, body rocking, or toe walking. Engagement in more complex routines or ritualistic behavior may also be present in older children and adults (Loveland & Tunali-Kotoski, 2005). Individuals with ASD often insist on sameness and have difficulty coping with change or tolerating stimuli that are new or not-preferred. When routines are disrupted or when an individual is pushed to tolerate stimuli outside of his or her comfort zone, he or she may become very upset and engage in tantrum behavior (Eveloff, 1960; Kanner, 1951).

Another type of behavior that falls into the above category includes stereotyped play. Children may engage in a limited repertoire of play activities and may be preoccupied with a particular toy or part of a toy and may play in an unusual way (Mauk, Reber, & Batshaw, 1997). For example, a child may line up his or her toys rather than play with them functionally. The child may become very upset if the play is disrupted. Children with ASD may spin or flick the wheels of a car rather than drive it around or may lie on the floor to visually inspect objects rather than play with them. Higher order behavioral presentations in this category may include perseveration on specific topics and interests that are unusual in intensity and nature for their age (Kanner, 1943; Van Krevelen, 1971). For example, an individual may be fascinated with the history of light bulbs and may have difficulty engaging in conversations on other topics. The

depth of knowledge would be unusual, and the individual may be upset if not able to spend time focused on the restricted interest.

Prevalence of ASD

In addition to dramatic shifts in awareness in the past five decades, there have also been dramatically shifting diagnostic criteria and nomenclature. As one can imagine, prevalence estimates of autism have changed greatly since the disorder was first identified and named in the 1940s. Early prevalence estimates put the disorder at 2 per 10,000 in the 1970s (Gillberg & Wing, 1999; Kawamura, Takahashi, & Ishii, 2008; Waterhouse, 2008). It is important to remember that at that time, ASD continued to be misdiagnosed as the criteria were not yet listed in diagnostic manuals as its own disorder. Since that time, prevalence estimates have continued to rise. Currently, estimates range from 1 in 68 to 1 in 150 children depending on the procedures used to collect data (CDC 2014; Fombonne, Quirke, & Hagen, 2009; Lord & Bishop, 2010; Matson & Shoemaker, 2009; Nicholas et al., 2008). Throughout all the changes, there have consistently been a significantly higher proportion of males diagnosed, with a ratio of 4:1 to 5:1 consistently being reported (CDC, 2014; Fombonne, 2003).

Regarding diagnostic criteria, the DSM-III-R criteria were found to be too broad (Volkmar et al., 1994), a pendulum swing from the narrow criteria found in the DSM-III. More recently, a significant shift in criteria with DSM-5 has narrowed criteria significantly (Maenner et al., 2014; Lobar, 2016; Matson, Hattier, & Williams, 2012; Tsai, 2014; Worley & Matson, 2012). It is estimated that 9-54% (median = 30%) of those meeting criteria under the text revisions of the DSM-IV do not meet criteria under the DSM-5. In addition to changing criteria and increased awareness, diagnostic substitution has been reported; specifically, as the prevalence of ASD has increased, the prevalence of ID has decreased. Polyak, Kubina, and

Girirajan (2015) found that the decrease in ID accounted for 64.2% of the increase in ASD in children between the ages of 3-18 years.

In addition to increasing awareness, changing criteria, and diagnostic substitution, researchers point to other factors that impact the rise of reported prevalence. A study by Matson and Kozlowski (2011) reviews many of these factors, and the researchers suggest additional factors based on a review of prevalence studies. They note that the method for assessment of ASD has continued to change with younger and younger children being diagnosed in an environment of increasingly diverse assessment tools. Research methodology also varies among studies with some diagnoses being parent reported, others gleaned from examination of educational classification data, and others from clinical assessment. In addition, they found that studies report on varying ages, with a consideration that milder cases are often diagnosed at later ages. Matson and Kozlowski (2011) also point out that premature infants now have a much greater survival rate than they have had in the past, and studies show that neurodevelopmental disorders, including ASD, are more prevalent in that population.

The recent increase in the prevalence of ASD has been noted in several countries with similar findings related to cause. Kawamura and colleagues (2008) posit that the 11 fold increase in Toyota, Japan noted between the 1970s and the 1990s resulted from inclusion of high-functioning individuals as well as an integrated process of screening. In the United Kingdom, Baron-Cohen and colleagues (2009) estimated a prevalence of 1% based on a survey of children aged 5-9 years, and factors contributing to the steep increase in prevalence were reported to include changes in diagnostic criteria and screening tools, changes in study designs, increased knowledge and awareness about ASD, improved health services, and increases in parental acceptance of ASD.

Prognosis, Treatment, and Outcomes

ASD is considered a life-long disorder. Although once considered untreatable (Kanner, 1951; Lotter, 1978), empirically supported treatment including early intensive behavioral intervention (EIBI) can have a meaningful impact on developmental trajectories, with varying outcomes reported (Howlin, 1998; Lovaas 1987). However, autism symptoms remain life-long despite the potential for symptom amelioration (Billstedt, Gillberg, & Gillberg, 2005; Ecker, Bookheimer, & Murphy, 2015; LoVullo & Matson, 2009).

Evidence-Based Intervention

There exists a substantial body of research in support of a behavioral approach to the treatment of autism, specifically, the use of ABA to mitigate symptoms of ASD in children (Carr & Firth, 2005; Dawson & Osterling, 1997; Lovaas, 1987; Rogers, 1998). Behavioral strategies were first employed in the early 1960s and culminated in the development of a comprehensive treatment approach that focusses on EIBI (Carr & Firth, 2005; Fisher, & Zangrillo, 2015). Effective components include behavioral strategies consistent with operant and classical conditioning. Strategies include systematic desensitization, social skills training, modeling, reinforcement, shaping, exposure, graduated guidance, prompting, chaining, discrete trials, and fading (Fava et al., 2011; Ganz et al., 2011; Lerner & Mikami, 2012; Matson, Adams, Williams, & Rieske, 2013; Patterson, Smith, & Jelen, 2010; White et al., 2011). The most well-known treatment package was developed by Dr. O. Ivar Lovaas and consists of up to 40 hours per week of comprehensive, intensive, home-based intervention provided by trained therapists in a 1:1 setting with a focus on discrete trial training. Other packages focus on different components, but generally, the approach is the same, and they would fall under the umbrella of EIBI. Other approaches with emerging evidence to support efficacy include more parent-focused intervention

with lower intensity including the Early Start Denver Model (ESDM) and Hanen's More Than Words program. Both of these programs focus on toddlers. The ESDM utilizes ABA in a naturalistic setting and stresses parental involvement, a developmental sequence, and relationship development and is geared for children between the ages of 12 and 48 months (Rogers et al., 2012). Hanen's More Than Words program for toddler up to age 5 years includes eight sessions of parent training sessions provided by a speech-language pathologist and focuses on increasing social communication during everyday activities (Carter et al., 2011). Government committees and professional groups in several countries have published treatment guidelines to stress the importance of utilizing a scientific basis for the treatment of ASD (Dillenburger, 2011).

Barriers to Treatment

Unfortunately, families often have difficulty accessing appropriate services (Krauss, Gulley, Sciegaii, & Wells, 2003; Ruble, Heflinger, Renfrew, & Saunders, 2005). In a study by Bowker, D'Angelo, Hicks, and Wells (2011), 23% of children with ASD were found to have never received treatment based on a sample of 970 parents who reported via an online survey about treatment use. Many others used treatments lacking empirical support. Ruble and colleagues (2005) reported on their state's Medicaid Managed Care program from 1995-2000. They found that, based on prevalence rates, only one-tenth of individuals with autism utilized services. Further, the type of services provided transitioned from day treatment to medication management and case coordination over time. Results from a national survey by Krauss and colleagues (2003) suggested that over a third of individuals with autism had difficulty with access to care, specifically related to getting appropriate referrals and finding providers with adequate training. Compared with children with ID, of whom one fifth had access problems, those with ASD were at a distinct disadvantage. Coordination of care was found to be almost

three times more likely to be a difficulty for parents of children with autism compared with children with other types of healthcare needs. Further, they found that poor parental health exacerbated difficulty with access. The researchers also found there were significantly more problems with insurance (e.g., getting referrals, insurance paying for services, insurance approving the appropriate number of visits), specifically if they had a diagnosis of autism versus another type of special health need or ID.

Several factors have been identified as barriers to early intervention including lack of health insurance, poverty, difficulty accessing specialty care, lack of regular medical care, and minority status (Palmer, Walker, Mandell, Bayles, & Miller, 2010). Another barrier to early intervention may be related to living in a rural environment. Delays in service provision have been reported due to shortages of professionals within particular disciplines (e.g., physical therapy) and general shortages in rural areas, with two regions in Louisiana highly affected by these concerns (Office for Citizens with Developmental Disabilities [OCDD], 2012).

Barriers to appropriate services have been found to disproportionately impact children with ASD who are of a minority status. They are less likely to use services, are more likely to start services at a later age, and are less likely to access evidence-based intervention compared to non-minority white children (Levy, Mandell, Merher, Ittenbach, & Pinto-Martin, 2003; Mandell et al., 2002; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Levy and colleagues (2003) reviewed 284 charts from the Regional Autism Center of The Children's Hospital of Philadelphia, Pennsylvania and found that Latino children were more likely to use complementary and alternative medicine rather than evidence-based interventions. Racial disparity in treatment has been cited in early intervention programs in two states including Minnesota, where counties with higher percentages of African-American children had lower

overall rates of enrollment (Chan & Obnsorg, 1999) and Massachusetts, where referrals to Part C were lower for premature infants of African-American mothers than for other racial and ethnic groups (Barfield et al., 2008). In another study, African-American infants and toddlers between the ages of 9 and 24 months were half as likely to receive early intervention compared with white peers and were also less likely to receive services compared to other races (Rosenberg, Zhang, & Robinson, 2008).

Unfortunately, the treatment that is recommended for those with ASD is not easy. It is recommended that children start very early in life, and when the diagnosis is delayed, a natural barrier exists. Further, the treatment is very intensive, meaning that parents often have difficulty, logistically speaking, in implementing procedures. Waitlists are often prohibitively long, costs are often prohibitively high, and insurance often does not cover all the costs. In some cases, a specific diagnosis is required before insurance will cover service provision, and insurance often caps coverage before the minimum number of recommended hours is implemented. Parents who are less "savvy," less informed, or who have more life stressors are often not in a position to help their children effectively.

It is estimated that only 17% of children younger than age 5 years who were classified as having a developmental delay receive services for their delays (Simpson, Colpe, & Greenspan, 2003). Palmer and colleagues (2010) identified factors that delay receipt of services generally, including lack of health insurance, poverty, difficulty accessing specialty care, and lack of regular medical care.

Age of Treatment Onset

Dawson and Osterling (1997) found that best treatment outcomes in those with ASD symptoms are associated with approaches with high intensity (i.e., high number of weekly

treatment hours, low child to teacher ratios), high amount of structure and consistency, and curriculum that focuses on direct teaching of attending skills, imitation skills, language training, and social interactions. There is also a consistent research literature to suggest that better outcomes are found in children who start intervention earlier. Specifically, it is recommended that children receive two or more years of early intervention beginning by age 3 years or even as early as age 2 years (Hoyson et al., 1984; McEachin, Smith, & Lovaas, 1993; Peters-Scheffer et al., 2011; Rogers & Lewis, 1989; Sheinkopf & Siegel, 1998).

CHAPTER 3: DIAGNOSIS OF ASD

As stated above, ASD is diagnosed based on behavioral presentation. The diagnostic process is multi-faceted and includes a parent interview (to outline the developmental course thus far and to describe the day-to-day behavior), direct observation of the child, and the use of assessment tools to quantify development and symptoms (Matson, Beighley, Williams, & May, 2014; Rogers, 2001). Although parents often have concerns early in development, formal ASD diagnosis is frequently delayed, and ASD is often not diagnosed until age 4 or 5 years (Rogers, 2001). In some cases, initial concerns are addressed to the pediatrician who may not be aware of early and subtle symptoms of the disorder (Matson, Rieske, & Tureck, 2011).

Age of Diagnosis

Whereas ASD can be diagnosed reliably in toddlers by age 2 years and as young as age 17 months (Gray & Tonge, 2001; Matson, Rieske, et al., 2011, milder presentations (i.e., Asperger's disorder and PDD-NOS) often cannot be reliably diagnosed until age 4-5 years (Lord & Spence, 2006). The actual age of diagnosis tends to vary based on geographic area, year, diagnoses included, and study design. In one study of Pennsylvania families, mean age at diagnosis was 3.1 years for those with autistic disorder, 3.9 years for those with PDD-NOS, and 7.2 years for those with Asperger's Disorder (Mandell et al., 2005). A multi-site network to monitor prevalence utilized record review and found a median age of 4.1 to 5.5 years among sites (CDC, 2007). Another population-based study found a median age of 5.1 years for ASD diagnosis (Wiggins et al., 2006). Because these studies could not have captured those who had not yet been identified as they typically included children up to age 8 years, these ages are naturally underestimates of true means. In a survey of 770 children in the UK, the average age of diagnosis for those with autistic disorder was 5.5 years, whereas the average age for those with

Asperger's disorder was 11 years (Howlin & Asgharian, 1999). More recent examination of age of diagnosis suggests that the average age of ASD diagnosis has remained stable over the past several years, with an average age of 4.5 years, and children who do not evince a language or cognitive impairment are often not diagnosed until they enter school (CDC, 2014).

Based on a study of 56 parents in Canada, from the first discussion of concerns, most families waited almost three years to receive a diagnosis and saw an average of 4.5 professionals (Siklos & Kerns, 2007). In a study by Wiggins and colleagues, (2006), a mean age of 48 months was reported for age at initial evaluation and 61 months for age when an ASD diagnosis was given. Zuckerman, Lindly, and Sinche (2015) found that the mean lag between first conversation with a professional and diagnosis of ASD was 2.7 years, with minimal difference between those with or without ID (2.6 years and 3.0 years respectively). In their sample of 1282 children, 44% of those with ASD waited at least three years between first discussion about concerns and diagnosis. In the vast majority of cases, an ASD diagnosis requires a referral to a specialist (Johnson, Myers, & American Academy of Pediatrics Council on Children with Disabilities, 2007). With delays to diagnosis, there are lost years of potential early intervention and treatment. Not surprisingly, the long interval between recognition of delay by parents and provision of a diagnosis has a dramatic impact on parental stress (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011; Mansell & Morris, 2004; Osborne & Reed, 2008). Having an accurate ASD diagnosis and knowing that their child is receiving therapy may help parents to cope (Lord, Rutter, & Le Couteur, 1994). The lag also impacts parents' confidence in medical professionals (Harrington, Patrick, Edwards, & Brand, 2006).

The ultimate goal is for children with ASD to have a diagnosis before the age of 3 years so that ABA services can be initiated early (Rogers, 2001). Detection and diagnosis of ASD in

young children is essential for service provision, for developing an appropriate treatment plan, and for preparing parents to adapt to a child with a disability (e.g., learn to obtain information, access appropriate services, and advocate for their child; Chung, Smith, & Vostanis, 1995; Konstantareas, 1989, 1990; Nissenbaum, Tollefson, & Reese, 2002; Siegel, 1996).

Factors Impacting Age of Diagnosis

Data from 13 sites were studied as part of the Autism and Developmental Disabilities Monitoring (ADDM) Network (Shattuck et al., 2009). From a sample of 2,568 children aged 8 years diagnosed with ASD, the mean age at the time of diagnosis was 5.7 years. Gender was a significant factor with males diagnosed significantly earlier than females (ages 5.6 years and 6.1 years, respectively). Because cognitive impairment is more common in females with ASD, intellectual functioning was also examined by gender. In those without ID (i.e., IQ of 70 and above), females were diagnosed at a mean age of 7.1 years whereas males were diagnosed at a mean age of 6.5 years. In those with ID, children were diagnosed at younger ages with females diagnosed at a mean age of 5.5 years and males at 5.1 years. Another set of researchers further investigated gender differences in the ADDM study and concluded that females without ID were at higher risk for diagnostic delay (Giarelli et al., 2010). Shattuck and colleagues (2009) found a significant effect of ethnicity on age at the time of diagnosis with Hispanic children diagnosed latest (e.g., age 6.2 years).

Shattuck and colleagues (2009) also found that developmental regression impacted age of identification such that children who experienced regression were diagnosed at a mean age of 4.2 years whereas those who did not demonstrate loss of skills were diagnosed at a mean age of 6.2 years. Maternal age at conception and maternal education were inversely proportional to age at diagnosis. Age at diagnosis varied by part of the country; 14 states were represented with the

youngest age at diagnosis in West Virginia (age 5.1 years) and the oldest age at diagnosis in Arizona (age 7.3 years). Importantly, the researchers found that 27.1% of all cases meeting criteria for ASD according to the ADDM had no record of having been diagnosed, suggesting that they were unidentified through age 8 years.

Mishaal, Ben-Itzchak, and Zachor (2014) investigated 551 children between the ages of 15 and 72 months and found that, similar to the study by Shattuck and colleagues, developmental regression was associated with younger age at time of diagnosis. They also found that the severity of social impairment was also associated with younger age at diagnosis. The severity of repetitive behavior and restricted interest was associated with older age at diagnosis. In terms of family factors, they found that firstborn children were diagnosed at older ages compared with children who had an older sibling. In their study, there was no difference in age at diagnosis based on the age of parents at conception or parental education. Unlike the results from the ADDM study, no gender differences were found. Mandell and colleagues (2002) found differences in age of ASD diagnosis between Caucasian and African-American children. African-American children were diagnosed later. Potential causes for the disparity were suggested including differences in help-seeking behavior, access to care and support, and decision making of clinicians. Other researchers have also noted that minority status, less severe impairment, and lower socio-economic status are associated with delayed diagnosis (Mandell et al., 2002; Mandell et al., 2005; Mandell et al., 2009; Wiggins et al., 2006). Earlier diagnosis have been found to be associated with greater parental education and income (Goin-Kochel, Mackintosh, & Myers, 2006)

Delays are also associated with factors related to healthcare systems (e.g., waitlists, access to specialized services, provider responses). Although parents often bring up concerns to

healthcare providers who have frequent early contact with families, many providers do not adequately assess for developmental delays even for children known to be at risk (Guerrero, Rodriguez, & Flores, 2011; Zuckerman, Boudreau, Lipstein, Kuhlthau, & Perrin, 2009). Although the American Academy of Pediatrics outlines recommendations for standardized primary care-based screening for developmental problems and ASD (Johnson et al., 2007; Council on Children With Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee, Medical Home Initiatives for Children With Special Needs Project Advisory Committee, 2006), many primary care providers fail to follow guidelines for screening (Daniels & Mandell, 2013; Guerrero, Garro, Chang, & Kuo, 2010; Radecki, Sand-Loud, O'Connor, Sharp, & Olsen, 2011). An additional problem is that many primary care providers are not comfortable identifying children at risk for ASD (Zuckerman, Mattox, et al., 2013).

The role of the physician is primary in referring for adequate care (Ellerbeck, Smith, & Courtemanche, 2015). Families report that referral for diagnosis and treatment can be delayed by months or years after first bringing up concerns to their pediatrician (Carbone et al., 2013; Carbone & Farley, 2010; Howlin & Asgharian, 1999; Sices, Egbert, & Mercer, 2009). The primary care provider is, in essence, a gatekeeper, and may provide reassurance to families when they should, in fact, refer for ASD evaluation (Howlin & Asgharian, 1999). In one study, parents of children with ASD were more likely to get a passive/reassuring provider response than those with ID/DD, and proactive responses by providers were found to lead to a shorter delay to diagnosis (Zuckerman et al., 2015). These researchers also found that passive/reassuring provider responses were found to be associated with at least a year delay to diagnosis, which is not surprising as well-child visits are spaced out by one year after age 2.

CHAPTER 4: PARENTAL FIRST CONCERNS

When something is amiss with development, parents typically first become concerned before age 2 years. Means of first parental concern range from age 13 months (Fombonne, 1999; Kozlowski et al., 2011) to age 19.32 months (Howlin & Moore, 1997). However, many parents reported concerns before age 1 year (Kishore & Basu, 2011). Parents usually notice behavioral differences and abnormalities in children with ASD by age 24 months (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003; Chakrabarti, 2009; Chawarska et al., 2007; Young, Brewer, & Pattison, 2003), and in one study, for 78% of children, parents became concerned prior to their child's second birthday (Guinchat et al., 2012). Earlier recognition of symptoms on the part of parents is positively correlated with the time at which parents seek help for their child (Kozlowski et al., 2011).

Nature of First Concerns

Many researchers have pointed to communication problems including language and speech as the area of first concern noted by parents in those with developmental delays (DeGiacomo & Fombonne, 1998; Howlin & Moore, 1997; Kozlowski et al., 2011; Meek et al., 2012). Social problems were noted as the second most frequent first concern by several researchers (DeGiacomo & Fombonne, 1998; Howlin & Moore, 1997). In some studies, problems with social development were the most commonly reported first concern; this may be the case for those with an Asperger's like presentation where early language develops on time (Howlin & Asgharian, 1999).

Another common early concern about development is the presence of challenging behavior including aggression, self-injurious behavior, hyperactivity, and problems with sleep (DeGiacomo & Fombonne, 1998; Guinchat et al., 2012 Kozlowski et al., 2011). It is noted that

these problems are not diagnostic symptoms of ASD but are commonly reported in the population. Regression of skills in the above-mentioned areas is also sometimes noted by parents of children with ASD as well as problems with initial development in these areas (DeGiacomo & Fombonne, 1998). Although ritualistic and repetitive behavior is a diagnostic symptom in those with ASD, these concerns have not been found to be a common first concern in the studies mentioned above. In many cases, parents of children later diagnosed with ASD are concerned early-on regarding development in multiple areas, not surprising as ASD is considered to be pervasive. In one study, 31.2% of those with more than one first concern were diagnosed with ASD compared with 17.7% of those with one first concern (Matson, Mahan, Kozlowski, & Shoemaker, 2010).

Factors Impacting Parental First Concerns

As with age at the time of diagnosis, there are factors that have been found to impact the age at which parents first notice problems with development. First concerns have been noted to occur earlier when symptoms are more severe (Baghdadli et al., 2003) or when other medical problems exist during infancy (DeGiacomo & Fombonne, 1998). Toddlers later diagnosed with ASD have a significantly younger age of parental first concern versus those with atypical development (Kozlowski et al., 2011; Zuckerman et al., 2015).

Concerning family factors, DeGiacomo and Fombonne (1998) found a trend for a lower age of first concern by parents when the child had an older sibling, though this was not a significant factor in their study. It was suggested that this trend may represent a true difference as parents may have more experience to know when something was amiss. More research with larger sample sizes would be needed. Chawarska and colleagues (2007) also failed to find a meaningful difference between those children who had an older sibling and those children who

were firstborn (Chawarska et al., 2007). Differences in timing of first concerns were not found by Chawarska and colleagues (2007) based on the presence of a sibling with ASD. The researchers described this as a surprising finding and suggested that at the time of the study (conducted in 2000 and 2003), there may not have been an awareness of the higher risk for ASD in children who have a sibling with the disorder. They found that advanced maternal age was associated with delayed recognition of early concerns. The researchers pointed out that the reason for this is not clear, but may be related to the use of fertility treatment and difficulties getting pregnant that may have contributed to mothers being more accepting of developmental differences or to the higher prevalence in ASD in those with older parents. No difference in timing of parental first concern was found based on social class or ethnicity (DeGiacomo & Fombonne, 1998; Jang, Matson, Cervantes, & Konst, 2014), suggesting that other factors play a role in delayed diagnosis for low SES or minority families other than early parental concern about development.

There continues to be a question about how gender impacts first concerns, possibly because differences exist in the symptom profile and prevalence between males and females with ASD. Specifically, ID is more prevalent in females with the disorder, and more males are diagnosed with ASD compared to females in a ratio of approximately 4:1. In a study by Horovitz, Matson, Turygin, and Beighley (2012), the age of first concern was found to be lower for females. The same trend was found by DeGiacomo and Fombonne (1998), although the difference was not statistically significant in their small sample of females. However, no difference between genders was found in other studies (Volkmar, Szatmari, & Sparrow, 1993). Other researchers have reported that social concerns are less often noted for females, possibly as females are accepted as having a shy temperament (Bumiller, 2008; Guinchat et al., 2012; Miller,

2003). Guinchat and colleagues (2012) found no effect of the gender of the parent on early concerns.

CHAPTER 5: LAG TIME BETWEEN FIRST CONCERNS AND ACTION

Time Between First Concerns and Help Seeking or Diagnosis

Researchers have used different methodologies to study lag time, and it is important to consider regional differences in healthcare provision when comparing lag time. Some studies investigated the lag from first concern to help seeking whereas others investigated time from first concern to diagnosis. With first concerns typically noted in the first two years of life, it is not surprising that researchers suggest that from time of first concern, children may wait up to six years before they are diagnosed (Goin-Kochel et al., 2006).

Howlin and Moore (1997) used a questionnaire to gain information from parents retrospectively regarding age of first concerns and the diagnostic process. A total of 1295 forms were completed by parents living in the United Kingdom, and the rate of returns was 53.1%. Children were between the ages of 2 and 49 years at the time of data collection. Parents were found to first become concerned about their child's development at a mean age of 1.69 years, and they first sought help at a mean age 2.3 years (Howlin & Moore, 1997). On average, the researchers reported a lag of 6-7 months from time of first concern to help seeking. However, much variation was found such that 23.7 percent waited up to 12 months and another 9.4 percent waited up to 2 years before seeking professional help. In one case, the lag was over 10 years. The mean age at eventual diagnosis was 6 years suggesting a lag of 4.31 years from time of first concern to diagnosis. Sixty-eight percent of those children were diagnosed with autism or Asperger's Disorder, and another 26.7% were labeled as having "autistic tendencies." At the time of first discussing concerns (most often with a health visitor or general practitioner but in some cases a pediatrician), 7.8% received a diagnosis. Over half of these children were referred to another professional, 25% were reassured that there was no problem and they "should not

worry," 6.5% were told to return if worries persisted, and 4.2% were told that the child "would grow out of it."

In another study conducted by Howlin and Asgharian (1999) using a survey of 770 children collected as part of the study described above by Howlin and Moore, lag was further investigated for those diagnosed with autism and Asperger's disorder separately. For those diagnosed with autism, the mean age at parental first concern was 18 months. With mean age at time of diagnosis found to be 5.5 years, a lag of 4 years to diagnosis was reported for those with autism (n = 614). For those with Asperger's disorder (n = 156), the researchers found a much longer lag between first concern and diagnosis with parental first concern noted at a mean age of 30 months and diagnoses occurring at a mean of age 11 years. In a population-based study conducted in Sweden, a delay of 20-60 months between parental concerns and diagnosis was found (Sivberg, 2003).

DeGiacomo and Fombonne (1998) studied 82 children (mean age of 6 years) who were referred in the United Kingdom to a clinic for those with Pervasive Developmental Disorders between the years of 1993 and 1996. All met criteria for ASD as defined by ICD-10 criteria. Information was collected using the Autism Diagnostic Interview-Revised. The mean age reported by parents for the time when they first became concerned about their child's development was reported to be age 19.1 months while they reported that they first sought professional advice at a mean age of 24.1 months. A mean lag of 5.2 months (SD = 7.0 months) was found for the group. Professional advice was most often consulted from health visitors and general practitioners. A strength of the study was that children were relatively young at the time of data collection.

In Japan, researchers collected information from parents with children aged 1- 48 years (Fujiwara, Okuyama, & Funahashi, 2011). Questionnaires were disseminated to parents with a child with ASD in person and were returned by mail. Response rate was found to be 34%. Using responses from 1,513 parents with children younger than 19 years, they found a mean age of first parental concern of 4.7 years (SD = 3.7). Mean lag time between parental first concern and first visit with a child psychiatric center was 2.9 years (SD = 3.0; range 0.01-23 years).

In France, Guinchat and colleagues (2012) designed a questionnaire consisting of forced-choice and open-ended questions to be completed by parents to assess difficulties with the diagnostic process for their child with ASD. The questionnaires were sent to parents by mail and by email. Four hundred fifty-nine questionnaires were returned from parents with children ranging in age from younger than 5 years and older than 18 years (mean age 12.6 years). The rate of return was stated to be less than 50%. The mean age of children when parents first became concerned about their child's development was age 19 months (SD = 11.7 months). Parents first sought the advice of a professional at a mean age of 27 months (SD = 17.5 months), a lag of 5.2 months (SD = 11.7) between concern and action on the part of the parent, whereas the mean lag between first concern and receipt of diagnosis was 39.3 months (SD = 44.4).

In a recent study conducted in the United States, Zuckerman and colleagues (2015), researchers at Children's Hospital Oregon Health and Science University and Oregon State University, studied lag time between first concern and ASD diagnosis. They used data from the 2011 Survey of Pathways to Diagnosis and Treatment, a national study of children with ID/developmental delay and ASD. Children were between the ages of 6 and 17 at the time of the survey. Based on results from 3,158 parents, lag time ranged from 0.1 years to 0.4 years between first concern and first discussion of concerns with a provider. It is noted that these researchers

recorded whole number of years only, rather than age or time in months. For example, children between the ages of 12 and 23 months were recorded as being 1 year old.

Factors that Impact Lag Time Between First Concerns and Action

Whereas many studies discuss factors impacting timing of age of first concern or age at diagnosis, few studies directly examine lag time between first concern and when a parent acts on that concern. Relevant studies of factors relating to lag time are outlined in Table 1. The earliest study to investigate factors contributing to lag time was conducted in 1998 by DeGiacomo and Fombonne as described earlier in this paper. They found several factors that impacted the age of first concern; however, they failed to find significant factors specific to lag time. Factors found not to impact lag included gender, birth order, social class, and type of diagnosis.

In the study by Fujiwara and colleagues (2011), factors associated with a longer lag included: those who were younger at the time of the initial concern, living with younger siblings; social or behavior problems/not attending school; caregivers who lacked knowledge of where to go; longer commutes; longer wait times. Factors associated with shorter lag included: older age at first concern, living with child's father, and having a developmental delay. Several factors were not found to be associated with lag time including: child's gender, socioeconomic status, and degree of impairment. Regarding age at first concern, a wide age range was included, and the researchers found that parents who had concerns before the age of 1 year experienced a long lag. When first concerns were between ages 1-3 years, there was not much difference in lag compared to when concerns were noted between 3-5 years. However, there was a large difference in lag time for older children such that children who were 6-12 or 13-18 at age of first concern did not wait as long. The difference was attributed to shorter wait times for older children and adolescents.

Table 1

Relevant Studies of Factors Impacting Lag Time Between First Parental Concern and Action

Study	*n*	Age Group	Mean Lag Time	Method	Significant Factors	Other Factors Studied
DeGiacomo & Fombonne (1998)	82	Mean: 6 years (SD = 3.1)	Before getting professional advice: 5.2 months (SD = 7.0)	Diagnostic interview	None	Gender, birth order, social class, type of diagnosis
Fujiwara, Okuyama, & Funahashi (2011)	4,323	Range: 1-18 years	Before visiting a child psychiatric center: 2.9 years (SD = 3.0)	Retrospective questionnaire	Shorter lag: older age of first concern, living with child's father, having developmental delay Longer lag: younger age of first concern, living with younger siblings, social/behavior problems/not in school, lack of caregiver knowledge of process, longer commute, longer wait times	Child's gender, socioeconomic status, degree of impairment
Guinchat et al. (2012)	459	Mean: 12.6 years Range: < 5 years to > 18 years	Before seeking advice of professional: 5.2 months (SD = 11.7)	Retrospective parent report by mail. Open ended questions.	Shorter Lag: no language, verbal communication problems, concerns reported by the father Longer Lag: stereotypes/restricted behavior, non-specific concerns	Other types of parental concerns
Zuckerman, Lindly, & Sinche (2015)	3,158	Range: 6-17 years	Before discussing concerns with provider: 0.1-0.4 years	Retrospective survey	Shortest Lag for those with ASD and ID Longest Lag for those with ASD only	None

The study earlier described by Guinchat and colleagues (2012) also investigated factors contributing to lag between first concern and advice seeking from a professional. Specifically, they considered 26 variables related to type of parental concerns coded in 10 domains and 16 subcategories. Shorter lags were found when parents reported that the child had no language, verbal communication problems, or when concerns were reported by the father. Longer lags were found when concerns included stereotypies or repetitive behavior or when non-specific concerns were reported.

Zuckerman and colleagues (2015) compared children with ID or developmental delays (DD) only to those with ASD only and those with ASD and co-occurring ID and found, consistent with past research, a lower age of first concern by parents of children with ASD. They then compared the time lag between first concerns and discussion with a provider among the groups and found a lag of 4.8 months for those with ASD/no ID, 3.6 months for those with ID/DD/no ASD, and 1.2 months for those with ASD and ID.

CHAPTER 6: EARLY INTERVENTION

Within the United States, each state has an early intervention program as specified by the Individuals with Disabilities Education Act (IDEA), Part C. IDEA, Part C is a federal grant program established by Congress in 1986 with a goal to provide no-cost services to infants and toddlers age 0-36 months and their families for those at risk of, or diagnosed with, a developmental delay. Qualifying conditions include developmental disabilities as well as medical diagnoses including cerebral palsy, infant diabetes, epilepsy, neurofibromatosis, deafness, blindness, tuberous sclerosis, genetic disorders, and premature birth.

In Louisiana, the early intervention program is called EarlySteps; other states use similar names that imply a call to action such as Strong Start, Babies Can't Wait, Help Me Grow, First Steps, SoonerStart, and Baby Watch. Early intervention is a systematic approach to promote development in infants and toddlers up to age 3 years (Kaur et al., 2006; OCDD, 2012). Intervention often involves working on physical skills or motor skills (e.g., reaching toward a desired item, rolling, crawling, walking, picking up small items), language and communication building (e.g., talking or communicating nonverbally with signs, body language, or by exchanging pictures), enhancing cognitive skills/problem solving, social/emotional skills (e.g., sharing, playing appropriately), and self-help/adaptive skills (e.g., eating, dressing; OCDD, 2012). Most of the services provided by EarlySteps occur in a child's natural environment in order to facilitate service delivery and also to improve the family's ability to enhance development, a goal of EarlySteps (OCDD, 2013).

The state of Louisiana defines developmental delay as an individual scoring 1.5 standard deviations below the mean in the development of cognitive skills, physical abilities, communication skills, social skills, or adaptive skills (OCDD, 2012). Vision and hearing

problems, abnormal sensory responses, and problems with emotional development or affective disorders would also meet the criteria for service eligibility in Louisiana (OCDD, 2012). In addition to serving individuals who have been identified as having a developmental delay, EarlySteps serves infants and toddlers with a medical condition that may result in a developmental delay, putting them in the "at risk" category.

The Office for Citizens with Developmental Disabilities (OCDD), part of the Louisiana Department of Health and Hospitals, published outcomes of EarlySteps (2012). They noted improvements in social and educational skills, reductions in cost of more intensive services later in life (e.g., special education, healthcare), reductions in parental stress and frustration, improvement in challenging behavior, and increases in productivity and independence. Eighty percent of parents credited EarlySteps with helping them to know and understand their rights as well as to effectively communicate their children's needs, critical skills necessary to advocate for a child with a disability (OCDD, 2013).

Early intervention programs are not typically intensive programs; however, gains have been positively correlated with intensity of interventions (Symes, Remington, & Brown, 2006). More and more states are providing 20 or more hours per week of ABA services through their IDEA, part C program. Ohio became one of these states in September of 2013, following a lawsuit brought forth by parents of a two-year-old denied provision of recommended services (Young v. State of Ohio, 2013).

In Louisiana, referrals to EarlySteps may be made by anyone. The most common referral source is the family (OCDD, 2013), and calls can be placed directly to EarlySteps. The second most common referral source is a doctor, and the third is a hospital. Healthcare professionals are mandated by Federal law to refer children to the early intervention program if they are suspected

of having a developmental delay. There are stringent goals regarding the time between the date that the referral is placed and eligibility determination (45 days).

CHAPTER 7: PURPOSE

The aim of the current study was to investigate factors that predict the time lag between parental first concern and entry into Louisiana's early intervention program, EarlySteps. The study included three parts. First, the intent was to identify child and family factors, including demographic variables, that may predict lag time. Second, there was an aim to establish differences in lag time based on the nature of parental first concerns. The first two parts of the study focused on variables that can be used to predict lag time. The third aim was to determine if, retrospectively, there were factors related to the child's symptom presentation that predict lag time.

Early and intensive treatment for those with ASD is critical for optimal outcomes. Therefore, it is important that these factors are clarified so that at-risk populations can be targeted with effective routes to enter treatment programs as quickly as appropriate. Researchers have established that when delays in development are experienced by a child, parents are attuned to these delays and notice concerns very early. Across studies, parents first report concerns between the ages of 13 and 19 months (Fombonne, 1999; Howlin & Moore, 1997) and often before the age of 1 year (Kishore & Basu, 2011). Despite early recognition of problems by parents, often, parents do not act on these concerns in a timely manner. The lag is alarming, particularly because even after parents bring up a concern to a healthcare provider, it can still take years before a formal diagnosis is provided. This is true despite the development of assessment tools in recent years that can be used with younger children and toddlers. Many hurdles exist in connecting with services that are typically not within parents' scope of control. Increasing our understanding of family and child factors that impact lag time can help bridge the

gap between concern and treatment, irrespective of system barriers that are typically more difficult, and often more expensive, to address.

Prior to the current study, only four studies had investigated factors that contribute to a lag time between parental first concern and action (see Table 1). In addition to a scarcity of research, another issue when considering what is known about factors relating to lag time is that prior studies were all conducted in different countries where differing healthcare systems make comparison among studies difficult. Further, it was common for studies investigating lag time and related factors to utilize questionnaires broadly distributed to parents of children with ASD. Response rates ranged from 34%-53% (Fujiwara et al., 2011; Guinchat et al., 2012; Howlin & Moore, 1997), indicating that results of studies may not be representative despite large sample sizes. The only study of lag time using direct collection of data was somewhat smaller (n = 82), and the authors failed to find any significant factors (DeGiacomo & Fombonne, 1998). Finally, studies were often conducted retrospectively which can lead to inaccurate reporting of ages of affected children. When a long time interval exists between the age at which parents become concerned about their child and when the parents report the information, there is a tendency to report an older age of recognition, termed the "telescoping effect" (Cooper, Kim, Taylor, & Lord, 2001).

The current study's use of an IDEA, Part C early intervention sample mitigated the effect of system-level barriers which likely were a factor, even if not accounted for, in the four previous studies. Because parents are the most common referral source in an EarlySteps sample, the role of the pediatrician as gatekeeper was minimized. Further, wait times were less of a factor because there are timelines for enrollment into programs, and diagnosticians are not part of the process. Finally, the telescoping effect was minimized, as all respondents in the present study

have children younger than age 3 years, and information was collected directly rather than retrospectively or via mailed surveys.

Part 1: Impact of Child and Family Factors on Lag Time

Only two prior studies have investigated child or family factors that may contribute to the lag between first concern and action (DeGiacomo & Fombonne, 1998; Fujiwara et al., 2011). Regarding child and family factors, the study by Fujiwara and colleagues (2011) was the only one to find significant results. They found a shorter lag when the child lived with his or her father and a longer lag when the child lived with younger siblings. Gender and socioeconomic status were not significant factors in their study. DeGiacomo and Fombonne (1998) investigated gender, birth order, and social class but found no significant factors. A limitation of their study was a relatively small sample size of 82.

Although, thus far, researchers have failed to find a connection between a child's gender and lag time (DeGiacomo & Fombonne, 1998; Fujiwara et al., 2011), there are studies to suggest that parents of females recognize first concerns earlier (Horovitz et al., 2012; DeGiacomo & Fombonne, 1998) but are diagnosed later than males (Giarelli et al., 2010; Shattuck et al., 2009). Other studies have found no difference in age of first concern based on gender (Volkmar et al., 1993), but even so, a difference in lag would be expected with later diagnosis. It has been posited that gender differences may result from differences in cognitive functioning (Rivet & Matson, 2011). The role of gender needs further study accounting for overall level of functioning to clarify the literature in this area.

The role of ethnicity has not been studied as it relates to lag time. Fujiwara and colleagues (2011) included socioeconomic status as a factor but did not find that it played a role in lag time. However, it was noted that the nature of Japan's healthcare system may have resulted

in less disparity in that population. In other studies, ethnicity and social status have been found not to affect age of first concerns (DeGiacomo & Fombonne, 1998; Jang et al., 2014). However, disparities in age of diagnosis have been documented by several researchers (Mandell et al., 2002; Mandell et al., 2005; Mandell et al., 2009; Shattuck et al., 2009; Wiggins et al., 2006), suggesting that differences in lag time are likely.

The purpose of Part 1 was to further investigate the role that child or family factors play in predicting the lag between first concern and action. The five factors that were included in the analysis were gender of the child, ethnicity of the child, age when the parent first became concerned about the child's development, birth order of the child, and the presence of an immediate family member with ASD. The entire sample was studied first to establish whether any of the factors predict lag time for toddlers across the sample. Following that, three subgroups based on the toddler's overall functioning level were analyzed using a Low, Borderline, and Average or Above cutoff based on the developmental quotient score from the Battelle Developmental Inventory. Cutoffs corresponded with scores used to diagnose Intellectual Disability (for the Low subgroup) and Borderline Intellectual Functioning (for the Borderline subgroup). The purpose of using clinically significant subgroups was to account for overall functioning level as lag time has been found by some researchers to be impacted by the presence of a developmental delay (Fujiwara et al., 2011) or the presence of ID (Zuckerman et al., 2015). The following hypotheses were offered for Part 1:

1. Age of first concern was hypothesized to predict lag time for the total sample and for all subgroups. Those with older ages of first concerns (e.g., those who became concerned at age 34 months) could not have had long lag times because children age out of the EarlySteps program at 36 months. Therefore, shorter lags were

expected for those with higher ages of first concern. Conversely, when parental concerns begin at or around the time of the child's birth, wait time would be at least 16 months and possibly up to 37 months (age range in the sample).

2. It was hypothesized that the Low subgroup would have shorter lags than the Borderline subgroup which would have shorter lags compared to the Average/Above subgroups. Rationale for the above was based on the results of the study by Zuckerman and colleagues (2015) which found that those with ID had shorter lags than those without ID.
3. It was hypothesized that, for the total sample, there would be a significant impact of gender such that there would be a longer lag time for females as opposed to males. Researchers have found younger age of first concern for females (Horovitz et al., 2012; DeGiacomo & Fombonne, 1998) or no difference in timing of first concerns between males and females (Volkmar et al., 1993). However, females were consistently diagnosed later than males (Giarelli et al., 2010; Shattuck et al., 2009). Although two previous studies failed to find a significant effect of gender on lag to parental action, the studies may not be as likely to find differences due to the telescoping effect. Specifically, one study included parents of children up to age 18 years (Fujiwara et al., 2011). Results of two studies suggest that specifically, females without ID are more at risk for diagnostic delay (Giarelli et al., 2010; Shattuck et al., 2009). As such, it was hypothesized that gender explains the most variance in lag time for the Average/Above subgroup whereas it was hypothesized that it would not be a significant indicator of lag time for the Low subgroup because severity of deficits would overshadow gender effects.

4. It was hypothesized that ethnicity would be a significant factor impacting lag time for the total sample and for all subgroups. Researchers have found that the age when parents become concerned about their child's development does not vary based on ethnicity (DeGiacomo & Fombonne, 1998; Jang et al., 2014). However, minority status has been recognized as a barrier to early intervention (Barfield et al., 2008; Chan & Obnsorg, 1999) and has been found to be linked with a later age of ASD diagnosis (Mandell et al., 2002; Mandell et al., 2005; Mandell et al., 2009; Shattuck et al., 2009; Wiggins et al., 2006). As such, a longer lag time is likely to be experienced by minorities.
5. It was hypothesized that birth order would predict lag time for the total sample and for the Average/Above subgroup but not for the Low subgroup. Research regarding the role of birth order on timing of parental concerns is not definitive. A trend for earlier concerns in later-born children have been noted by some (DeGiacomo & Fombonne, 1998), but those researchers and others failed to find a statistically significant impact of birth order on age of first concern (Chawarska et al., 2007). If age of first concern was not earlier in later-born children, but later-born children are diagnosed earlier (Mishaal et al., 2014), it is thought that there would be an effect of birth order on lag time such that later-born children benefit from their parent's increased understanding of development and have a shorter lag. It was hypothesized that this effect would be less pronounced in the Low subgroup, as delays would be so pronounced that birth order would not predict lag in that subgroup.

6. Finally, it was hypothesized that the presence of an immediate family member with ASD would impact lag time for the total sample and for all subgroups. Only one previous study investigated how the timing of parental concerns was impacted by the presence of a sibling with ASD, and researchers did not find significant results. It was postulated by those researchers that this was due to an older sample and a lack of awareness at that time period that ASD was more likely in families that already had a child with ASD. As such, it was proposed that, in a more recent sample, parents may be more aware of risk, may be more familiar with pathways to services, and may understand the importance of early action.

Part 2: Impact of Parental First Concerns on Lag Time

Two prior studies have addressed the nature of first concerns and their effect on lag (Fujiwara et al., 2011; Guinchat et al., 2012). Regarding the nature of first concerns, a group of researchers have found shorter lags to be associated with an older age of first concern, such that older children and adolescents received psychiatric services sooner than younger children (Fujiwara et al., 2011). It was cautioned that this was likely a result of different healthcare pathways for older children and shorter wait times. Additionally, the type of parental concern appears to impact lag time with shorter lags reported when language problems are reported and when concerns are reported by the father (Guinchat et al., 2012). Alternatively, the researchers found longer lags when concerns were non-specific or when the concern was related to repetitive or restricted behavior. Because only two studies have investigated the role that parental concerns play on lag time, more research is needed in this area.

Part 2 of the study sought to determine whether the type and number of parental first concerns contribute to the lag time between first concern and entry into EarlySteps. For this part of the study, the total sample was used. Parental first concerns were coded, and four groups were created including those who were only concerned with language development (Language Only group), those who were concerned with language development and one other concern including either social problems or behavior problems (Language + One group), those who were concerned about three or more specific areas of development (Multiple group), and those who were concerned generally about development, but did not report specific concerns (Global group). The following hypotheses were offered for Part 2:

1. It was hypothesized that significant differences would be found among groups. Because previous researchers found that the longest lag was found in those who reported non-specific concerns (Guinchat et al., 2012), it was hypothesized that the longest lag would occur in the Global group.
2. The shortest lag time was expected for the Multiple group as it was thought that parents would feel more urgent about the need for intervention when concerns across domains were present.
3. It was hypothesized that the Language group would have a longer lag than the Language + One group, as more concerns may translate to a quicker response from parents. Further, language development tends to be the area of development with the most variation in what is considered normal (Bickerton, 1984; Rivers, 2016). Because it is difficult for parents to discern what is a delay and what is at the lower end of normal, it was proposed that in the absence of other concerns, parents who are only concerned about language may be more likely to wait longer

to act on their concerns compared to cases where there is another concern in addition to language.

Part 3: Impact of Symptom Presentation on Lag Time

Three of the prior studies of lag time included clinical presentation or type of diagnosis as factors that may impact lag time. Zuckerman and colleagues (2015) found that when ASD and ID were both present, lags were shortest, whereas when ASD was present without ID, lags were longest. Children with only ID fell in the middle with regard to lag time. DeGiacomo and Fombonne (1998) did not find that type of diagnosis impacted lag time in their sample. Finally, Fujiwara and colleagues (2011) found a shorter lag time when a developmental delay was present but found that the degree of the impairment did not impact lag. They also found that the presence of behavioral and social problems was associated with a longer lag. Differences among the studies may be attributable to differences in samples, region, and methodology. Part 3 of the current study attempts to clarify the ambiguities noted in the current literature.

Part 3 of the current study was designed to investigate the impact of eventual symptom presentation on lag time. Specifically, factors investigated include the presence or absence of ASD, the impact of ASD symptom severity, and the degree of overall impairment as measured by DQ. Part 3 was conducted as a follow-up to Part 1, thus included significant variables found in Part 1 and extended the study to predict, retrospectively, how the child's measured symptoms may impact lag time, irrespective of demographic and family factors that would be known prior to entry into the EarlySteps program. As with Part 1, the analysis for Part 3 was conducted for the total sample and repeated with the Low, Borderline, and Average/Above subgroups. The following hypotheses were offered for Part 3:

1. Generally, it was hypothesized that the Low subgroup would have the highest autism symptom scores and the highest prevalence of ASD. Alternatively, the Average/Above subgroup was expected to have the lowest autism symptom scores and the lowest prevalence of ASD.
2. Based on the results of the study by Zuckerman and colleagues (2015) that those with ID and no ASD had longer lags than those with ASD and ID, the shortest lag was expected for those with ASD in the Low subgroup, and the presence of ASD was hypothesized to predict lag time in the Low subgroup.
3. When ASD severity was significant, it was hypothesized that social and language problems would predict lag time whereas more severe repetitive behavior would not impact lag time. Repetitive behavior has not been found to be an area of first concern in the literature.
4. Concerning the DQ, it was hypothesized that this variable would be directly proportional to wait time for the overall sample as other researchers have found a shorter lag time for those with ID (Zuckerman et al., 2015). Fujiwara and colleagues (2011) found that the presence of a developmental delay was associated with shorter lag times whereas the degree of delay was not associated with lag time. As such, it was hypothesized that DQ would not be a significant factor in the Low subgroup.

CHAPTER 8: METHOD

Participants

Participants for the current study were toddlers and their caregivers recruited throughout the state of Louisiana; all participants were enrolled in Louisiana's EarlySteps program, and the legal guardian consented to participate in research. Data used was garnered from a pre-existing database that is part of an ongoing study of children with developmental delays. The database currently contains assessments from the EarlySteps program collected between the years 2008 and 2015. In total, there were 15,250 administrations in the database. Of those, 8,971 were cataloged as a first administration, indicating that they were administered at the time of entry into the EarlySteps program. The remainder was not included in the study as they were either annual evaluations that were administered to assess progress or were exit evaluations which were administered when the child no longer qualified to receive EarlySteps services. Of those 8,971 assessments, 11 were removed because a current age for the child was not reported, or the age was outside of the range for the assessment tools (i.e., older than 37 months). In many cases, the caregiver did not report an age when they first became concerned about the child's development, resulting in 2,660 administrations being removed, and a further 23 were removed because the age of first concern was greater than the current age, suggesting a reporting error or a data entry error. An additional 1,990 cases were removed due to an incomplete total score on the measure of autism symptoms, and 65 cases were removed due to a missing developmental quotient score or a score outside of the range for the test (i.e., lower than 40 or higher than 160). Finally, seven administrations were deleted due to errors in the database when it was determined that specific administrations were entered in duplicate. Therefore, 4,215 assessments were retained in the current study as administered to children at the time of entry into Louisiana's EarlySteps

program, whose parents/caregivers consented to the ASD portion of the study, who were given a developmental battery, and who reported a valid age at which they first became concerned about the child's development. Participants were toddlers ranging in age from 16 to 37 months.

Participants were administered a battery of tests including the *Battelle Developmental Inventory, Second Edition (BDI-2*; Newborg, 2005) to acquire the DQ, a standardized score suggestive of overall development. The DQ, while not synonymous with an IQ score, has been used in the literature to approximate the IQ of very young children as traditional IQ assessments have not been found to be reliable in the first years of life (Davis et al., 2011). To delineate subgroups, participants were assigned to one of three groups based on overall functioning level: the Low subgroup included those with DQ scores less than 70, the Borderline subgroup included those with DQ scores from 70 to 84, and the Average/Above subgroup included those with DQ scores at or above 85. The Low subgroup contained 701 participants, the Borderline subgroup contained 1,654 participants, and the Average/Above subgroup contained 1,860 participants. Characteristics of the participants for Part 1 are presented in Table 2.

Table 2

Part 1 Participant Characteristics of the Total Group and Subgroups

	Total Sample *N* = 4,215	Low *n* = 701	Borderline *n* = 1,654	Average/Above *n* = 1,860
Age				
Range (months)	16-37	16-36	16-35	17-37
Mean (months)	24.8	25.2	24.9	24.6
Standard Deviation (SD)	4.5	4.8	4.6	4.2
Gender				
Male	70.4%	73.8%	73.1%	66.8%
Female	29.4%	26.1%	26.7%	33.1%
Missing	0.1%	0.1%	0.2%	0.1%

(Table 2 continued)

	Total Sample *N* = 4,215	Low *n* = 701	Borderline *n* = 1,654	Average/Above *n* = 1,860
Ethnicity				
Caucasian	53.1%	43.9%	49.0%	60.2%
African-American	34.6%	42.7%	38.3%	28.3%
Hispanic	4.2%	4.6%	4.3%	4.1%
Other	6.4%	7.0%	6.7%	5.8%
Missing	1.7%	1.9%	1.7%	1.6%
Developmental Quotient				
Range	45-130	45-69	70-84	85-130
Mean	82.1	62.5	77.1	94.0
Standard Deviation	13.1	5.3	4.4	7.2

Measures

Battelle Developmental Inventory, Second Edition (BDI-2; Newborg, 2005)

The *BDI-2* is a standardized, norm-referenced instrument designed to assess the developmental functioning of children from birth through age 7 years, 11 months. It is an informant- and observation-based assessment consisting of 450 items across five domains including adaptive, personal-social, communication, motor, and cognitive skills. Caregivers rate each item as 0 (no ability in this skill), 1 (emerging ability in this skill), or 2 (ability in this skill). The total score, a global measure of development, called the DQ is similar to an IQ score with a mean of 100 and a standard deviation of 15. The *BDI-2* has robust psychometric properties with excellent internal consistency between .85 and .99 on domains, subdomains, and global score as well high inter-rater reliability (Newborg, 2005).

Baby and Infant Screen for Children with aUtIsm Traits-Part 1 (BISCUIT-Part 1; Matson, Boisjoli, & Wilkins, 2007)

The *BISCUIT-Part 1* is part of a larger, comprehensive assessment battery designed to assess autism symptomatology, comorbid psychopathology, and challenging behavior in children between the ages of 16 and 37 months (Matson et al., 2007). The battery takes approximately 20-30 minutes to administer and includes an additional observational component. The purpose of

Part 1 of the battery is to aid in the diagnosis of ASD and to measure treatment gains. As such, it contains items to assess autism symptomatology including each of the three core symptom domains of ASD including socialization impairments, communication deficits, and the presence of restricted/repetitive behaviors and/or interests. Informants (parents or primary caregivers) are asked to compare their child to his/her same-aged typically developing peers. Part 1 consists of 62 items which are rated as "0" to indicate "not different; no impairment," "1" to indicate "different; mild impairment," or "2" to indicate "very different; severe impairment." Items are read aloud to the informant and, in the instance that a parent has difficulty comparing to same-aged peers, the assessor can refer to an appendix containing provider information about typical development and attainment of skills and milestones that can help the informant provide a rating.

A total score, the sum of all item scores, ranging from 0 to 124, is calculated and compared with established cutoffs to determine whether the child meets a threshold for an ASD diagnosis. A score of 0 through 16 is indicative of no ASD/atypical development, a score of 17 through 38 is indicative of possible ASD/PDD-NOS, and a score of 39 or higher is indicative of probable ASD/autistic disorder (Matson, Wilkins, Sharp et al., 2009). A three-factor structure was found with 24 items loading on factor 1 (socialization/nonverbal communication), 23 items loading on factor 2 (repetitive behavior/restricted interests), and seven items loading on factor 3 (communication).

The *BISCUIT-Part 1* has been found to be a valid measure of autism symptomatology (Matson, Wilkins, & Fodstad, 2011) with convergent and divergent validity comparisons with the *Modified Checklist for Autism in Toddlers* (Robins, Fein, Barton, & Green, 2001) as well as domains of the *Battelle Developmental Inventory, Second Edition* (Newborg, 2005). Internal consistency was found to be excellent with an alpha value of .97 (Matson, Wilkins, Sevin, et al.,

2009). Part 1 of the *BISCUIT* has an overall correct classification rate of 88.8% with sensitivity found to be 93.4% and specificity found to be 86.6% (Matson, Wilkins, Sharp, et al., 2009). As such, the *BISCUIT-Part 1* is one of the most psychometrically sound instruments for assessing core symptoms of ASD in toddlers.

BISCUIT-Demographic Form

The *BISCUIT* includes a one-page demographic form containing items to gain information about the child and the family. It also includes items to garner information related to parental concerns about their child's development/behavior (i.e., age at which concerns were first noted, space to specify the nature of concerns). Child information includes gender, age, birth weight, ethnicity, height, weight, age of milestone attainment (e.g., related to mobility, language development, and toileting skills), medical history, medication use, and ASD assessment history. Information about the family includes relationship of the informant to the child, number of siblings, birth order, and information about the presence of ASD in family members.

Procedure

Data were collected with the approval of the Louisiana State University Institutional Review Board and Louisiana's OCDD. Informed consent was obtained from parents or legal guardians. Trained test administrators conducted a comprehensive assessment for EarlySteps as part of the eligibility determination and also to establish the degree of the child's developmental delay to be used as baseline information. Following a referral to the program, assessments were conducted in the child's home or daycare setting with the child and parent/caregiver present. Assessments included direct observation of the child and collection of demographic information as well as completion of assessment measures. Test administrators were certified or licensed practitioners in relevant areas of study including psychology, early childhood development,

social work, special education, physical therapy, occupational therapy, and speech/language pathology. They held at least a bachelor's degree, were experienced in assessment and intervention with young children, and were trained on the administration of the test battery as well as ASD symptoms. Items from the measures were read aloud to parents/legal guardians, who were also provided an opportunity to ask questions.

Parental first concerns were coded according to the nature (type and number) of the responses given. Because the item asking about the nature of the first concern(s) is open-ended, there were many different responses given. However, by far, concerns about language development or communication were the only first concern listed for the vast majority of the sample (n = 2,636). Common responses for first concern included: "not talking," "language," "communication," "verbal communication," "speech," and "stopped using words." In addition to the "Language Only" group, three other groups were included in the analysis to investigate the impact of the nature of first concerns on lag time. The "Language + One" group included caregivers who listed language development and either behavior problems (e.g., tantrums, aggression, hyperactivity, behavior) or social problems (e.g., does not interact with others, social skills, eye contact) as the first concern (n = 432). The "Multiple" group included those caregivers who reported having three or more specific concerns about their child's development (n = 108). Finally, the "Global" group included those caregivers who indicated that they were concerned about "everything" or indicated that they had global or overall concerns about their child's development (n = 149).

Diagnoses of ASD were made by a licensed psychologist with over 35 years of experience in the diagnosis of ASD and other intellectual disabilities. Diagnostic decisions were

made based on scores on the *BISCUIT-Part 1* and *BDI-2*. For the present study, *DSM-5* criteria for ASD were used.

Statistical Analyses

Part 1

A multiple regression was conducted to determine what child and family factors predict the lag time between parental first concerns and entry into early intervention. The outcome variable was lag time (in months) between parental first concerns and entry into EarlySteps. The variable was calculated by subtracting the age at which the caregiver reported that he/she first became concerned about the child's development from the age at the time of the first EarlySteps assessment. Predictor variables included the following: child's age at the time of the first concern, gender of the child, ethnicity, birth order, and presence of an immediate family member with ASD. The procedure was conducted first using the total sample and then repeated for each of the three subgroups broken down by level of functioning: Low, Borderline, Average/Above.

The direct entry method was used to conduct the multiple regressions, so that all predictor variables were entered simultaneously (Tabachnick & Fidell, 2013). Collinearity diagnostics were examined prior to conducting the multiple regression to eliminate from subsequent analyses any variables with a tolerance value below .1 and a VIF value greater than 10 as such values can result in misleading results (Field, 2009; Leech, Barrett, & Morgan, 2008). At least 20 participants for every predictor variable are required for multiple regression (Leech et al., 2008); thus, at least 100 participants were necessary to conduct the analysis. For the current study, the total sample, as well as each of the subgroups, met this minimum requirement for sample size.

Part 2

The nature of the parental first concerns was investigated to determine the impact that the type and number of first concerns have on lag time. The lag time between age of first concern and age at entry into EarlySteps was compared among the four types of first concerns (Language group, Language + One group, Multiple group, and Global group) using an Analysis of Variance (ANOVA) procedure. Group membership was the independent variable (IV) and the lag time was the dependent variable (DV). The total sample was used for this analysis. Covariates were included for factors that were found to be significant in Part 1, if those factors did not differ among the four groups for Part 2 as shown by results of ANOVA. For a significant main analysis, follow-up post hoc tests were used to identify where the differences lie while controlling for familywise error with a Bonferroni correction (Field, 2009; Tabachnick & Fidell, 2013).

Part 3

To determine if the eventual symptom profile affects lag time, a second set of regression analyses was conducted. The outcome variable was lag time, and the predictor variables included diagnostic group (ASD or no ASD), ASD severity (total score on the BISCUIT part 1), and DQ. Any significant predictors from Part 1 were included as predictor variables. The regression was completed for the entire sample and then for each subgroup based on DQ as described in Part 1. In cases where ASD severity was significant, an additional multiple regression was conducted to parse out which symptom (i.e., language, social, repetitive behavior/restricted interest) was driving the difference by utilizing the factor scores on the BISCUIT part 1 (Matson, Boisjoli, Hess, & Wilkins, 2010) as the predictor variables.

CHAPTER 9: RESULTS

To ensure that the sample was large enough to achieve adequate power, a priori power analysis was conducted using G*Power 3 (Faul, Erdfelder, Lang, & Buchner, 2007). As is common for studies in the behavioral sciences, this study has a desired power of 0.80 and alpha was set at 0.05 (Cohen, 1988; Hinkle, Wiersma, & Jurs, 2003). With a desired effect size of .10, the minimum number of participants for the multiple regression for Parts 1 and 3 of the study was determined to be 647. The total sample and each of the subgroups met the above criteria for sample size. For Part 2, the minimum number of participants was found to be 279 for an ANCOVA with one covariate and a desired effect size of .25. The following analyses were conducted using SPSS 23.0.

Part 1: Impact of Child and Family Factors on Lag Time

The mean lag time for the total sample was found to be 7.9 months. Regarding the subgroups broken down by level of functioning (DQ), the longest lag time was found for the Low subgroup (9.3 months) and the shortest lag time was found for the Average and Above group (7.3 months). An ANOVA procedure was used to determine that subgroups differed, $F(2, 4{,}212) = 23.48$, $p < .001$, and Bonferroni corrected post hoc pairwise comparisons indicated significant differences between all subgroups ($p < .05$). The mean age of first concern also differed significantly among subgroups, $F(2, 4{,}212) = 10.83$, $p < .001$. Bonferroni corrected post hoc pairwise comparisons specified that age of first concern significantly differed between the Low and Borderline subgroups ($p < .01$), the Low and Average/Above subgroups ($p < .001$), but not between the Borderline and Average/Above subgroups. Descriptive statistics for the predictor variables not included in Table 1 can be found in Table 3.

Table 3

Part 1 Outcome and Predictor Variable Characteristics

	Total Sample	Low	Borderline	Average and Above
	N = 4,215	*n* = 701	*n* = 1,654	*n* = 1,860
Lag Time				
in months, *M (SD)*	7.9 (6.6)	9.3 (7.2)	8.0 (6.5)	7.3 (6.3)
Range in months	0-35	0-34	0-33	0-35
Family Member with ASD				
Yes	3.1%	5.3%	3.4%	1.9%
No	94.2%	92.2%	93.7%	95.5%
Missing	2.7%	2.6%	2.9%	2.6%
Birth Order				
M (SD)	2.1 (1.6)	2.2 (1.4)	2.1 (1.3)	2.0 (1.2)
Range	1-10	1-10	1-9	1-8
Median	2	2	2	2
Age at the time of first concern				
in months, *M (SD)*	17.0 (6.7)	15.9 (7.3)	16.9 (6.8)	17.3 (6.5)
Range in months	0-34	0-33	0-34	0-33

Lag time information for each of the relevant variables can be found in Table 4 along with Pearson's correlation coefficient between each predictor variable and the outcome variable for the total sample as well as each of the three subgroups. For the ethnicity variable, caregiver responses of African-American, Hispanic, and "Other," were collapsed into a group labeled "Minority."

The multiple regressions were conducted in accordance with the procedure outlined by Field (2009). Assumptions for multiple regression were assessed for the total sample and for the three subgroups. Multicollinearity was assessed by inspection of correlations between predictor variables. No two predictor variables had a correlation greater than 0.9, as such, predictor variables were assumed not to correlate too highly. The highest correlation was between birth order and the ethnicity, $r = 0.159$ for the Borderline subgroup. The outcome variable, lag time, is

continuous, and the predictor variables are continuous (i.e., age at time of first concern, birth order) or categorical with two categories (i.e., ethnicity, gender, family member with ASD). In addition, all tolerance values were well over 0.1, and all VIF values were found to be less than 10. The Durbin-Watson test yielded values of 1.584, 1.884, 1.654, and 1.737 for the total sample, Low subgroup, Borderline subgroup, and Average/Above subgroup respectively, all values close to 2 and within the range to suggest that errors are independent. Visual inspection of P-P Plot suggested that the assumption of normality was met. Leverage values were found to be below 0.2, and Cook's distance values were all below 1.

Table 4

Relationship of Lag Time and Predictor Variables

	Lag time, *M (SD)*			
	Total Sample	Low	Borderline	Average and Above
Gender				
Male	7.89 (6.37)	9.26 (7.03)	8.07 (6.32)	7.13 (6.02)
Female	7.90 (7.08)	9.20 (7.49)	7.80 (7.01)	7.60 (6.97)
r value	0.003	0.005	-0.017	0.034
Ethnicity				
Caucasian	7.54 (6.40)	8.30 (6.66)	7.83 (6.60)	7.11 (6.16)
Minority	8.33 (6.78)	10.09 (7.48)	8.21 (6.45)	7.55 (6.59)
r value	0.059***	0.120**	0.029	0.028
Family Member with ASD				
Yes	7.86 (6.37)	9.50 (5.59)	8.05 (6.94)	5.80 (5.75)
No	7.95 (6.56)	9.35 (7.23)	8.07 (6.47)	7.33 (6.31)
r value	0.001	0.004	0.004	-0.031
Birth Order				
r value	0.062***	0.08*	0.053*	0.047*
Age at first concern				
r value	-0.775***	-0.774***	-0.766***	-0.780***

Note: * $p < .05$; ** $p < .01$; *** $p < .001$

For the regression analysis of the total sample, inspection of casewise diagnostics suggested that there were three potentially influential cases with leverage values greater than 0.005 (the calculated value of three times the average; range of 0.008-0.01) and Mahalanobis distance values greater than 25 (range of 31.5-39.1). Investigation of data points suggested that all variables were within the established range, and no obvious data entry errors were present. Because Cook's distance was less than 1 (range of 0.001-0.004), there was no indication that the data points were unduly impacting the regression model. Therefore, the cases were all maintained for the analysis.

Table 5 shows the unstandardized regression coefficients (*B*), standard error of *B*, the standardized regression coefficients (β), amount of R^2 that is attributable to unique sources (sr^2), and R^2 for the total sample. The regression was significant, F (5, 3,936) = 1,203.03, $p < .001$, with an R^2 value of 0.60 and an adjusted R^2 value of 0.60.

Table 5

Multiple Regression for the Total Sample of Age of First Concern, Gender, Ethnicity, Birth Order, and Family History of ASD on Lag Time to Entry into Early Intervention N = 3,942

	B	*SE B*	β	sr^2
Constant	20.42	.22		
Age at First Concern	-0.76	0.01	-.78*	.597
Gender	-0.54	0.15	-.04*	.001
Ethnicity	0.69	0.13	.05*	.003
Birth Order	0.07	0.05	.01	.000
Family History of ASD	-0.24	0.38	-.01	.000

Note: $R^2 = .60$. *$p < .05$

When the analysis was repeated including only the Low DQ subgroup (i.e., those with DQ scores lower than 70), the inspection of casewise diagnostics indicated six cases with leverage values greater than 0.009 (the calculated value of three times the average; range of 0.0091-0.028). Mahalanobis distances were all within the accepted range (maximum value

18.23). Investigation of data points suggested that all variables were within the established range, and no obvious data entry errors were present. Cook's distance was less than 1 (range of 0.009-0.022) for all cases; therefore, the cases were all maintained for the analysis.

Table 6 shows the unstandardized regression coefficients (*B*), standard error of *B*, the standardized regression coefficients (β), amount of R^2 that is attributable to unique sources (sr^2), and R^2 for the low subgroup. The regression was significant, F (5, 656) = 200.51, $p < .001$, with an R^2 value of 0.60 and an adjusted R^2 value of 0.60.

Table 6

Multiple Regression for the Low Subgroup of Age of First Concern, Gender, Ethnicity, Birth Order, and Family History of ASD on Lag Time to Entry into Early Intervention n = 662

	B	*SE B*	β	sr^2
Constant	20.94	0.57		
Age at First Concern	-0.76	0.024	-.77*	.585
Gender	-0.54	0.40	-.03	.001
Ethnicity	0.92	0.36	.06*	.004
Birth Order	0.08	0.13	.02	.000
Family History of ASD	-0.32	0.78	-.01	.000

Note: $R^2 = .60$. *$p < .05$

For the regression analysis of the Borderline subgroup (i.e., DQ scores of 70-84), inspection of casewise diagnostics suggested that there were four cases with leverage values greater than 0.0039 (the calculated value of three times the average; range of 0.018-0.023) and which had a Mahalanobis distance value greater than 25 (range of 28.0-35.5). Investigation of data points suggested that all variables were within their established ranges, and no obvious data entry errors were present. Because Cook's distance was less than 1 (range of 0.020-0.036) for all data points, there was no indication that the data points were unduly impacting the regression model. Therefore, the cases were all maintained for the analysis.

The results of the regression can be found in Table 7, which includes the unstandardized regression coefficients (*B*), standard error of *B*, the standardized regression coefficients (β), amount of R^2 that is attributable to unique sources (sr^2), and R^2 for the total sample. The regression was significant, F (5, 1541) = 446.08, $p < .001$, with an R^2 value of 0.59 and an adjusted R^2 value of 0.59.

Table 7

Multiple Regression for the Borderline Subgroup of Age of First Concern, Gender, Ethnicity, Birth Order, and Family History of ASD on Lag Time to Entry into Early Intervention

	B	*SE B*	β	sr^2
Constant	20.33	0.35		
Age at First Concern	-0.74	0.02	-.77*	.588
Gender	-0.66	0.24	-.05*	.002
Ethnicity	0.70	0.22	.05*	.003
Birth Order	0.02	0.08	.00	.000
Family History of ASD	-0.01	0.58	.00	.000

Note: $R^2 = .59$. *$p < .05$

Finally, the Average/Above subgroup (i.e., those with DQ at or above 85) was analyzed. Inspection of casewise diagnostics suggested that further investigation of one case was warranted with a leverage value of 0.33 (greater than the 0.0035 cut-off as calculated) and a Mahalanobis distance of 57.7. No obvious data entry errors were present, and Cook's distance was less than 1 (0.39). Therefore, the case was maintained for the analysis.

Table 8 shows the unstandardized regression coefficients (*B*), standard error of *B*, the standardized regression coefficients (β), amount of R^2 that is attributable to unique sources (sr^2), and R^2 for the total sample. The regression was significant, F (5, 1727) = 542.36, $p < .001$, with an R^2 value of 0.61 and an adjusted R^2 value of 0.61.

Part 2: Impact of Parental First Concerns on Lag Time

Because group sizes differed significantly among groups and because distributions within groups were not normal, it was important to adjust sample sizes so that the largest group was no larger than 1.5 times the smallest group to ensure that the F-Test was robust to the violation of normality (Leech et al., 2008). Therefore, the Language Only group (n = 2,624) and the Language + One group (n = 428) were reduced using a random selection procedure and ensuring that the resulting sample was representative of the overall sample of each group. Regarding potential covariates, statistically significant results from Part 1 of this study were investigated. No significant differences were found among groups of the independent variable with respect to ethnicity [$\chi^2(3) = 5.26$, $p = .152$]. As such, ethnicity, which was found to predict lag time in Part 1, was retained as a covariate as it demonstrated independence with the independent variable. Gender was found to significantly differ among groups [$\chi^2(3) = 9.01$, $p < .05$] as did age of first concerns, $F(3, 577) = 74.79$, $p < .05$. As a result, gender and age of first concerns could not be included as covariates due to shared variance with the independent variable.

Table 8

Multiple Regression for the Average/Above Subgroup of Age of First Concern, Gender, Ethnicity, Birth Order, and Family History of ASD on Lag Time to Entry into Early Intervention

	B	*SE B*	*β*	sr^2
Constant	20.20	0.34		
Age at First Concern	-0.76	0.02	-.78*	.605
Gender	-0.34	0.20	-.03	.001
Ethnicity	0.41	0.19	.03*	.001
Birth Order	0.11	0.08	.02	.000
Family History of ASD	-0.89	0.68	-.02	.000

Note: $R^2 = .61$. *$p < .05$

An ANCOVA was conducted with lag time as the dependent variable, parental first concerns as the independent variable, and ethnicity as a categorical covariate. Levene's test of

equality of error variances was significant, indicating a violation of the assumption of homogeneity of variances, $F(3, 568) = 35.21$, $p < .001$. As a result, in order to control for Type 1 errors, alpha was set at .01 rather than .05 for the ANCOVA (Tabachnick & Fidell, 2013). Ethnicity, the covariate, was not significantly related to lag time, $F(1, 567) = 3.75$, $p = .053$. A significant effect of parental first concerns was found $F(3, 567) = 61.04$, $p < .01$, partial $\eta^2 = .24$. Bonferroni corrected post hoc analyses were conducted to determine which groups differed from one another. Results can be found in Table 9.

Table 9

Descriptive Statistics for Part 2 and Results of Bonferroni Corrected Post Hoc Tests

	Parental First Concern			
	Language Only *n* = 162	Language+One *n* = 162	Multiple *n* = 108	Global *n* = 149
Lag Time				
Mean (months)	6.33[cd]	7.02[d]	8.70[ad]	15.88[abc]
SD	5.01	5.63	6.83	9.40
Range (months)	0-26	0-24	0-33	0-35

Note: Alpha = .05 for Bonferroni post hoc analyses. Significant differences found with the Language Only group ([a]), Language+One group ([b]), Multiple group ([c]), and Global group ([d]).

Part 3: Impact of Symptom Presentation on Lag Time

Part 3 sought to further investigate factors that predict lag time including information about the child's eventual symptom profile. In addition to factors found to be significant in Part 1, factors added to the regression model included DQ, diagnosis of ASD according to DSM5 criteria, and ASD symptom total score as measured by Part 1 of the BISCUIT. See Table 10 for descriptive statistics relating to above mentioned variables. An ANOVA procedure was used to determine that subgroups significantly differed in scores of autism severity, $F(2, 4{,}212) = 888.74$, $p < .001$, and Bonferroni corrected post hoc pairwise comparisons indicated significant differences between all subgroups ($p < .001$). The percentage of children with or without ASD

was also found to significantly differ among subgroups [$\chi^2(2) = 508.52$, $p < .001$]. Table 11 contains information regarding the relationship between lag time and predictor variables.

Table 10

Part 3 Additional Predictor Variable Characteristics

	Total Sample	Low	Borderline	Average and Above
	N = 4,215	*n* = 701	*n* = 1,654	*n* = 1,860
DQ				
M (SD)	82.1 (13.1)	62.5 (5.3)	77.1 (4.4)	94.0 (7.2)
Range	45-130	45-69	70-84	85-130
Autism symptom score				
M (SD)	19.9 (18.3)	38.6 (23.4)	22.4 (16.5)	10.6 (9.0)
Range	0-116	1-116	0-108	0-87
ASD group				
Yes	14.1%	37.8%	16.2%	3.3%
No	85.6%	61.9%	83.8%	96.2%
Missing	0.2%	0.3%	0%	0.4%

Table 11

Relationship of Lag Time and Additional Predictor Variables

	Lag time, *M (SD)*			
	Total Sample	Low	Borderline	Average and Above
ASD symptom score				
r value	0.150***	0.163***	0.124***	0.049*
DQ				
r value	-0.118***	-0.174***	-0.075**	-0.011
ASD group				
ASD	9.58(6.92)	10.07 (7.04)	9.49 (7.05)	7.85 (5.46)
No ASD	7.61 (6.49)	8.76 (7.17)	7.70 (6.36)	7.26 (6.38)
r value	0.105***	0.087*	0.100***	0.017

Note: * $p < .05$; ** $p < .01$; *** $p < .001$

For the regression analysis of the total sample, inspection of casewise diagnostics suggested that there were three potentially influential cases with leverage values greater than 0.0017 (the calculated value of three times the average; range of 0.0079-0.014) and Mahalanobis distance values greater than 25 (range of 31.2-57.6). Investigation of data points suggested that all variables were within the established range, and no obvious data entry errors were present. Because Cook's distance was less than 1 (range of 0.005-0.012), there was no indication that the data points were unduly impacting the regression model. Therefore, the cases were all maintained for the analysis.

Table 12 shows the unstandardized regression coefficients (*B*), standard error of *B*, the standardized regression coefficients (β), amount of R^2 that is attributable to unique sources (sr^2), and R^2 for the total sample. The regression was significant, F (6, 4124) = 1073.21, $p < .001$, with an R^2 value of 0.60 and an adjusted R^2 value of 0.60.

Table 12

Multiple Regression for the Total Sample of Age of First Concern, Gender, Ethnicity, DQ, ASD group, and ASD Symptom Score on Lag Time to Entry into Early Intervention N = 4,128

	B	*SE B*	β	sr^2
Constant	21.17	.59		
Age at First Concern	-0.75	.01	-.77*	.584
Gender	-0.44	.14	-.03*	.001
Ethnicity	0.61	.13	.05*	.002
DQ	- 0.01	.01	- .02	.000
ASD Group	0.56	.26	.03*	.0004
ASD Symptom Score	0.01	.01	.03	.000

Note: $R^2 = .61$. *$p < .05$

For the regression analysis of the Low subgroup, inspection of casewise diagnostics suggested that of the cases with residuals outside of plus or minus two standard deviations, there were zero potentially influential cases with leverage values greater than 0.0087 (the calculated

value of three times the average) and Mahalanobis distance values greater than 25. Table 13 shows the unstandardized regression coefficients (*B*), standard error of *B*, the standardized regression coefficients (β), amount of R^2 that is attributable to unique sources (sr^2), and R^2 for the total sample. The regression was significant, F (5, 680) = 215.01, $p < .001$, with an R^2 value of 0.61 and an adjusted R^2 value of 0.61.

Table 13

Multiple Regression for the Low subgroup of Age of First Concern, Ethnicity, DQ, ASD Group, and ASD symptom score on Lag Time to Entry into Early Intervention n = 686

	B	*SE B*	β	sr^2
Constant	19.40	2.28		
Age at First Concern	-0.75	.02	-.76*	.555
Ethnicity	1.01	.35	.07*	.005
DQ	0.01	.04	.01	.000
ASD Group	0.20	.48	.01	.000
ASD Symptom Score	.022	.01	.07*	.003

Note: $R^2 = .61$. *$p < .05$

Because the ASD symptom score was a significant predictor of lag time, an additional analysis was conducted to determine which, if any, of the factor scores on the BISCUIT Part 1 were driving the significant results. As such, a regression analysis was conducted with age of first concern, ethnicity, and each of the three factor scores as predictor variables and lag time as the dependent variable (see Table 14). The total ASD symptom score could not be included as it was too highly correlated with Factor 3 (communication). None of the individual factors were significant, though the overall regression remained significant, F (5, 648) = 200.24, $p < .001$, with an R^2 value of 0.61 and an adjusted R^2 value of 0.60.

For the regression analysis of the Borderline subgroup, inspection of casewise diagnostics suggested that there were two potentially influential cases with leverage values greater than 0.0043 (the calculated value of three times the average; 0.019 and 0.023) and Mahalanobis

distance values greater than 25 (30.0 and 37.1). Investigation of data points suggested that all variables were within the established range, and no obvious data entry errors were present. Because Cook's distance was less than 1 (0.014-0.017), there was no indication that the data points were unduly impacting the regression model. Therefore, the cases were all maintained for the analysis.

Table 14

Multiple Regression for the Low subgroup including factor scores on the BISCUIT, n = 654

	B	*SE B*	*β*	sr^2
Constant	20.95	.821		
Age at First Concern	-0.74	.02	-.75*	.555
Ethnicity	0.913	.35	.06*	.004
Factor 1	0.04	.02	.07	.002
Factor 2	0.04	.03	.05	.001
Factor 3	-0.13	.07	-.05	.002

Note: $R^2 = .61$. *$p < .05$

Table 15 shows the unstandardized regression coefficients (*B*), standard error of *B*, the standardized regression coefficients (*β*), amount of R^2 that is attributable to unique sources (sr^2), and R^2 for the total sample. The regression was significant, F (6, 1616) = 392.90, $p < .001$, with an R^2 value of 0.59 and an adjusted R^2 value of 0.59.

For the regression analysis of the Average/Above subgroup, inspection of casewise diagnostics suggested that there were four potentially influential cases with leverage values greater than 0.0033 (the calculated value of three times the average; range of 0.018-.026) and Mahalanobis distance values greater than 25 (range of 33.0-48.2). Investigation of data points suggested that all variables were within the established range, and no obvious data entry errors were present. Because Cook's distance was less than 1 (range of 0.016-0.031), there was no

indication that the data points were unduly impacting the regression model. Therefore, the cases were all maintained for the analysis.

Table 15

Multiple Regression for the Borderline Subgroup of Age of First Concern, Gender, Ethnicity, DQ, ASD Group, and ASD Symptom Score on Lag Time to Entry into Early Intervention n = 1,623

	B	*SE B*	*β*	sr^2
Constant	21.10	1.95		
Age at First Concern	-0.73	0.02	-.76*	.575
Gender	-0.63	0.24	-.04*	.002
Ethnicity	0.63	0.21	.05*	.002
DQ	- 0.02	0.03	-.01	.000
ASD Group	0.72	0.38	.04	.001
ASD Symptom Score	0.01	0.01	.03	.000

Note: R^2 = .59. *p < .05

Table 16 shows the unstandardized regression coefficients (*B*), standard error of *B*, the standardized regression coefficients (*β*), amount of R^2 that is attributable to unique sources (sr^2), and R^2 for the total sample. The regression was significant, F (5, 1816) = 580.65, p < .001, with an R^2 value of 0.62 and an adjusted R^2 value of 0.61.

Table 16

Multiple Regression for the Average/Above subgroup of Age of First Concern, Gender, Ethnicity, DQ, ASD Group, and ASD symptom score on Lag Time to Entry into Early Intervention n = 1,822

	B	*SE B*	*β*	sr^2
Constant	23.73	1.35		
Age at First Concern	-0.77	0.01	-.79*	.612
Ethnicity	0.44	0.19	.03*	.001
DQ	- 0.03	0.01	-.04*	.001
ASD Group	0.59	0.62	.02	.000
ASD Symptom Score	-0.01	0.01	-.02	.000

Note: R^2 = .62. *p < .05

CHAPTER 10: DISCUSSION

Part 1: Impact of Child and Family Factors on Lag Time

Results of Part 1 indicate that, for the total group, lag time was predicted by age of first concern, gender, and ethnicity. For the Low and Average/Above subgroups, significant factors included age of first concern and ethnicity. For the Borderline subgroup, age of first concern, gender, and ethnicity were significant predictors of lag. Across all groups, a lower age of first concern and a minority status were associated with a longer lag.

Results indicate a significant effect of age of first concern on lag time. Consistent with Hypothesis 1, age of first concern was inversely proportional with lag time, meaning that those who were concerned at younger ages had a longer wait to enter services. The difference is largely an artifact of the nature of the data set. Because the age range for the sample was truncated, including only those from age 16-37 months, lag time could be larger when age of first concern was very small (e.g., when concerns were present from birth) and, similarly, when age of first concern was higher (e.g., close to the upper limit of age), the amount of lag possible was smaller. A large effect size (*r* of 0.77-0.78) was found for the relationship of age of first concern and lag time for the total sample and each of the subgroups.

Hypothesis 2 was related to the impact of gender on lag time. Gender was a significant predictor of lag time for the total sample, explaining 0.1% of variance in lag time. However, lag time between genders did not significantly differ for the total sample or any of the three subgroups. Although gender did not explain the most variance in the Average/Above subgroup as hypothesized, the largest mean difference in lag time between genders was found for the Average/Above subgroup in the direction predicted, such that females had a longer lag time than males (negligible effect size of $r = 0.034$). Unexpectedly, gender was a significant predictor of lag time for the Borderline subgroup with the directionality of the difference opposite what was

expected. For both the Low subgroup and the Borderline subgroup, females experienced a somewhat shorter lag as opposed to males. Although this difference was not significant, the trend is opposite that which was predicted. The complex relationship between gender, ID, and ASD may underlie these results. Specifically, in those with ASD, a lower gender ratio is found when ID is present (Rivet & Matson, 2011), though there is a dearth of research to explain the relationship between autism symptoms and IQ. Further, Rivet and Matson (2011) summarize research regarding gender biases in parent perception of social and communication difficulties that indicates a tendency for parents of girls to expect more in terms of social and communication skills and perceive more difficulties. As a result, it may be that parents of female toddlers may be more likely to act earlier on perceived delays and feel more tolerant of delays for males, with the rationale that it is expected for boys to be somewhat behind the overall average. It is unclear why, in that case, this pattern would not also occur for the Average/Above subgroup. The gender make-up of the Low and Borderline subgroups was different from the gender make-up of the Average/Above subgroup (33.1% compared with 26.1% for the Low subgroup and 26.7% for the Borderline subgroup) although this difference was not entirely unexpected with a higher prevalence of developmental disabilities in males. It is also offered that the age cut-off at the high end of the sample (37 months) may exclude more females later diagnosed with ASD than males as many may not have been identified early enough to qualify for EarlySteps services.

Hypothesis 3, that the Low subgroup would have the shortest lag and the Average/Above subgroup would have the longest lag, was not supported. The reason for this is likely related, in part, to a significant difference in age of first concern among groups. Because age of first concern was found to have a large effect size on lag, such that those with an earlier age of

concern had a longer lag, the overall pattern could result from the age of the sample included. That being said, it is concerning that a longer lag is present when overall functioning is impaired, as children with developmental delays should be more easily recognized as needing help.

Regarding ethnicity, the topic of Hypothesis 4, significant differences in lag time were found between Caucasians and minority groups for the total sample and for the Low subgroup. As hypothesized, ethnicity predicted lag time for the total sample and for all subgroups such that, for all groups, minorities had a longer lag time than Caucasians. The largest effect was found for the Low subgroup, for which 0.4% of the variance in lag time is explained by ethnicity. Mean differences in lag time related to ethnicity were most pronounced in the Low subgroup, where lag time was 10.09 months as compared to 8.30 months for Caucasians, representing a small effect size of $r = .12$. After age of first concern, ethnicity resulted in the largest and most consistent effect on lag time found in the analysis.

Hypothesis 5, relating to birth order, was not supported. There was a significant, positive correlation found between lag time and birth order for the total sample and for each subgroup; however, the effect size for the correlation was negligible (ranged from $r = .05$ to $r = .08$). It was hypothesized that birth order would predict lag time for the total sample with the highest amount of variance explained for the Average/Above subgroup, and it was thought that firstborn children would have a longer lag than later-born children. Birth order did not predict lag time for any group. It may be that, because birth order was entered as a continuous variable, the effect that was observed was more a result of family size rather than birth order. If the variable for birth order had been made dichotomous, with firstborn children compared with later-born children, the results may have been different. For the present analysis, a direct relationship for birth order (range of 1-10) and lag suggests that having more children in the home may result in longer lag,

possibly because of additional barriers and stressors that the family may experience when there are several siblings in the home.

Finally, for Hypothesis 6, little support was found. A small percentage of the total sample reported the presence of an immediate family with ASD (3.1%). For subgroups, the percentage of those with an immediate family member with ASD ranged from 1.9% (for the Average/Above subgroup) to 5.3% (for the Low subgroup). Significant differences in lag time were not found, possibly due to small proportions of the sample responding affirmatively to the item. The largest mean difference between those with and those without a family member with ASD was found for the Average/Above subgroup with a relatively large difference of 1.53 months (with a shorter lag time for those who reported having a family history positive for ASD), though the effect size was negligible (r = .03). Contrary to the hypothesis offered, the presence of an immediate family member with ASD did not predict lag time for any group. Additionally, the directionality of the difference in lag time for the Low subgroup was unexpected such that those with a positive family history of ASD had a somewhat longer lag time than those without a positive family history, though this difference was not significant.

Part 2: Impact of Parental First Concerns on Lag Time

The nature of parental first concerns was found to impact lag time after controlling for the effect of ethnicity. Specifically, the longest lag was found when parents had global or overall concerns rather than specific concerns. Hypothesis 1, that significant differences would exist among groups based on the nature of parental first concerns, was supported. Furthermore, as expected, the longest lag was found for the Global group, with a mean lag of 15.88 months. The group with the next largest lag was the Multiple group, with a lag of 8.70 months, a difference of 7.18 months. The finding that parents with non-specific concerns wait longer than parents with

specific concerns is consistent with Guinchat and colleague's study (2012). The long lag for the Global group indicates a need to help these parents to better understand developmental milestones across areas and early signs of ASD, as well as to pursue avenues for service provision.

Hypotheses 2 and 3 suggested that as the number of specific parental concerns increase, lag time would decrease. These hypotheses were not supported. The shortest lag was found when parents had one, specific concern about language development. When parents had a concern about language and one additional concern (i.e., concerns about either social development or behavior), lag time was larger, not smaller, compared to parents who were only concerned about language. The difference between the two groups was not significant, though the trend was an increase in lag with an additional concern. Similarly, when parents had three or more specific concerns, lag time again increased, resulting in a significantly longer lag as compared to parents with only a concern about language and a non-significant increase compared to parents with concerns in two areas (language and social development or language and behavior).

In Part 1, it was found that toddlers who did not evince a developmental delay (i.e., the Average/Above subgroup) had a significantly shorter lag time compared to those with a developmental delay (i.e., the Low and Borderline subgroups), which was explained, in part, by an earlier age of first concern in those with a developmental delay. It is likely that the finding related to functioning level and the finding related to number of concerns are related, such that parents of toddlers with a relatively high functioning level have fewer concerns. As such, it is suggested that the age of first concern, which was found in Part 1 to have a large effect on lag, is driving the difference among groups in Part 2 as well. In fact, age of first concern for the Global group (8.86 months) was found to be the lowest by far compared to the other groups,

specifically, 18.84 months for the Language group, 19.06 months for the Language + One group, and 15.68 months for the Multiple group. The non-significant difference between the Language Only group and the Language + One group could also be explained by the similar age of first concerns found between the two groups combined with the idea that problems with social interaction or behavior are related to communication difficulties in toddlers with delayed language development (Horwitz et al., 2003).

Another explanation for the general trend of increase in lag time with an increased number of specific concerns is related to symptom profile. It is possible that when a child is perceived to be doing well in most areas and struggling in only one area (Language Only group), the delay is more pronounced, as opposed to a child who appears to be struggling in several areas with more even development across domains (Multiple and Global groups). A more pronounced delay may explain a shorter lag. Parental attitudes also may be related to lag such that more perceived difficulties may be related to hesitancy to action due to ideas about social stigma related to developmental delays or feelings of denial about delays.

Part 3: Impact of Symptom Presentation on Lag Time

Additional information specific to the child's symptom profile was added to the regression model related to the presence of ASD, ASD severity, and DQ. ASD group predicted lag time for the total sample, ASD severity predicted lag time for the Low subgroup, and DQ predicted lag time for the Average/Above subgroup.

Hypothesis 1 was supported. Autism symptom score was highest for the Low subgroup and lowest for the Average/Above subgroup. ASD grouping also resulted in the largest proportion of individuals with ASD in the Low subgroup and the smallest proportion in the Average/Above subgroup with only 3.3% of the Average/Above subgroup.

Hypothesis 2, related to the presence of ASD was not supported. Firstly, it was hypothesized that the shortest lag would be found for those with ASD in the Low subgroup. However, this was not the case, as the No ASD group had shorter lags than the ASD group for those with DQs less than 70. Again, this is likely due, in part, to the age of first concern being lower in ASD group. Secondly, the ASD grouping predicted lag time for the total sample but not for the Low subgroup. In addition to child and family factors, the ASD group assignment predicted an additional .04% of the variance for the total sample, with a longer lag for those with ASD. The difference between those with ASD and those without was significant for the total sample, with a lag of 9.58 months for the ASD group and a mean of 7.61 months for the No ASD group, a small effect size. Previous researchers have found that parents of children with ASD were more likely to get a passive/reassuring provider response compared with parents of children with ID/DD. Passive responses were associated with longer delays to diagnosis (Zuckerman et al., 2015). As such, it is possible that longer lags in the current study are impacted by provider responses, which should be included in future studies about lag. Longer lags for those with ASD may also be associated with lack of education in parents and providers about early signs and symptoms of ASD.

ASD severity explained 0.3% of the variance in lag time for the Low subgroup with a small effect size noted. Hypothesis 3 proposed that significant factors within the ASD symptom score on the BISCUIT would include those related to social communication. However, possibly related to the size of the effect, none of the individual factors reached significance.

Hypothesis 4 was partially supported. A direct relationship between DQ and lag time was expected, however, an inverse relationship was found. Due to the nature of the relationship between age of first concerns and lag time in this study, those with more impairment, who,

overall, experienced an earlier age of first concern, had a longer lag. As such, age of first concern may explain, in part, the relationship between DQ and lag time. DQ was a significant predictor of lag time for the Average/Above subgroup, possibly due to the small proportion of those with ASD in the subgroup which resulted in little impact of the other symptom variables. The effect size of the relationship was negligible ($r = 0.05$). As predicted, DQ was not a significant factor to predict lag time for the Low subgroup as all of the toddlers in the group were experiencing overall delays and the degree of the delay was not indicative of lag.

General Discussion

An important finding, which was consistently found across all functioning levels, was the increased lag time between parental first concerns and entry into early intervention found for minority families compared with Caucasians. The difference was most pronounced for those with the most severe developmental delays (i.e., DQs lower than 70). Therefore, it is critical to attempt to reduce this disparity and facilitate timely involvement in early intervention for minority families. To do this, more information is needed to determine why the difference exists. More information about what may be impacting lag time will help to develop an effective plan moving forward. Additionally, it is important to ensure that minority families are informed about availability of services and the importance of evidence-based intervention, as researchers have found that minority families are less likely to use services and are more likely to use approaches that lack empirical support (Levy et al., 2003; Mandell et al., 2002; Thomas et al., 2007). Efforts should be made to encourage physicians to take care in appropriately addressing parental concerns, especially for minority families, considering that age of recognition of developmental problems was not found to differ among ethnic groups (DeGiacomo & Fombonne, 1998; Jang et

al., 2014). Other family factors that need to be explored which may be related to ethnicity include the effects of socioeconomic status, parental education, and geographic location.

Because of the large effect size found for the variable age of first concerns, those variables that are correlated with age of first concerns (e.g., symptom presentation and general rather than specific parental concerns) should be studied further to clarify their relationship to lag time. In the present study, the presence of ASD, more ASD symptoms, and lower DQs were associated with longer lag time, which are concerning findings. Other variables may be implicated in the above patterns. Parental attitudes need to be considered including feelings of social stigma related to disability, which have been found to differ based on culture, as well as feelings of denial about delays the child may be experiencing (Zuckerman, Sinche, et al., 2013). Other parent factors that should be studied include familiarity with developmental milestones, knowledge about ASD, and knowledge about accessing services. In the present study, the longest time lags were found when parents had general, rather than specific, concerns about development. When there is a lack of education about the above, lag could increase for those who need services most (i.e., those with ASD and those with low DQs.). Provider education about ASD (largely directed to pediatricians who have access to children at well-child visits) and provider responses to parental concern also would likely impact lag and may be related to symptom presentation limiting accessibility to services, specifically for those with ASD and global delays.

Strengths of the present study include the use of a large sample and the inclusion of toddlers as opposed to older children to decrease the impact of the telescoping effect, or recall bias, found using retrospective data. Further, the current study was unique in that the toddlers were all assessed using standardized measurement tools combined with direct interview and

observation. Previous studies of lag time mainly utilized samples with wide age ranges and used retrospective questionnaires disseminated to parents with children who were assessed in varying ways.

IDEA, Part C programs are available at no cost to parents until age 36 months and are available across the United States, making the current study exceedingly relevant. Improvement in service delivery through this modality is an optimal target to better address developmental problems. IDEA, Part C programs should be expected to provide appropriate services, including for those with ASD who require a more intensive approach as compared to toddlers whose delays are limited to speech and language problems. As laws change and insurance companies are held more accountable for providing treatment, and as IDEA, Part C programs continue to expand coverage of appropriate and intensive interventions for those with ASD, it is necessary to determine how to encourage parents to be more proactive. Considering that parental first concerns typically occur in the first two years of life, it is reasonable to suggest that children with ASD symptoms should optimally acquire at least one year of appropriate treatment while in the early intervention program operated by their state.

Lifetime costs associated with the treatment of an individual with ASD over a lifetime exceeds one million dollars in the United States, and early identification and evidence-based treatments can lessen long-term costs (Buescher, Cidav, Knapp, & Mandell, 2014; Jacobson & Mulick, 2000; Peacock, Amendah, Ouyang, & Gross, 2012). There is an awareness that it is necessary to improve polity, funding, wait times, and healthcare systems to provide early access to treatment for children with developmental disabilities. However, the ultimate goal is much broader, and that is to improve timely access to evidence-based services for all children who need it. As such, it is important to address child and family factors that can also be barriers to

appropriate care and that can be more readily, and cheaply, addressed as compared to systems level problems. With the general consensus that earlier is better in terms of outcome, it is important to address developmental problems as early as possible rather than waiting until a formal diagnosis is given, which can be delayed by years rather than months. By increasing our knowledge of who is “at risk” for too much delay, there can be action steps taken to improve access to appropriate treatment.

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