

Running Head: EARLY INTERVENTION SERVICES FOR ASD

**FACTORS ASSOCIATED WITH UTILIZATION OF EARLY INTERVENTION
SERVICES OF INDIVIDUALS DIAGNOSED WITH AUTISM SPECTRUM DISORDER**

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Abstract

Background: 1 in 59 individuals in the United States are diagnosed with ASD, with an average age of diagnosis of 4.7 years across all ethnic groups. Early intervention (EI) services can help improve developmental outcomes for those on the spectrum, when implemented early on. While age of diagnosis is critical for this, no studies have looked at which parent-related and other systemic factors have a direct association with and best predict EI. This study attempts to lay the ground work for further research on Early Intervention and how we can best reduce the gap in service utilization.

Methods: In this study, data from 1765 parents of children ever diagnosed with ASD, retrieved from 2011 Survey of Pathways to Diagnosis and Services were analyzed using Pearson Chi-squared Analysis, Spearman Correlation and Binary Logistic Regression to determine factors that best predicted EI.

Results: This study found significant differences across the age, parent concern, parent diagnostic experience and insurance domain between those that received EI and those that did not.

Conclusion: Age, along with parent concerns in the social/communication domain and secondary conditions best predict EI for this sample. Public health implications and directions for future research are discussed.

Dedication

“There needs to be a lot more emphasis on what a child can do instead of what they cannot do.”

-- Temple Grandin.

To the millions of individuals living with Autism Spectrum Disorder; this study is dedicated to you and was created and written while thinking about your individuality and the challenges you face every day.

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Introduction

Literature Review

Defining Autism Spectrum Disorder.

Autism Spectrum Disorders (ASD) is a neurodevelopmental disorder where individuals often display deficits in social and communication behaviors during early childhood (Lauritsen, 2013). Individuals with ASD also show delays and deficits within the behavioral domain, including having very limited, fixated interests and stereotypic, repetitive behaviors (Barbaro, & Dissanayake, 2009). Individuals with ASD experience limited non-verbal communication (such as gestures, eye contact, pointing, etc.), and the inability to form reciprocal relationships with peers. For a large proportion of children with ASD, limited communication abilities also result in difficulty in social interaction. While many experience delays in language development, some never acquire verbal communication skills (Barbaro, & Dissanayake, 2009). Individuals with ASD will also lack adaptive life skills and may have other psychopathologies (Matson & Nebel-Schwalm, 2007). Diagnosis of ASD is largely based on behaviors (Newschaffer and Curran, 2003).

Autism Spectrum Disorders is an umbrella term that is now being used to describe previous diagnostic terms of autistic disorder, Asperger's disorder, childhood disintegrative disorder and pervasive neurodevelopmental disorder not otherwise specified (Lord et al, 2012). ASD is a group of disorders on a continuum or "spectrum" ranging from mild to severe symptoms. Low functioning ASD individuals may be completely non-verbal (Seltzer et al., 2003), cognitively impaired (Ozonoff, Pennington & Rogers, 1991), have self-injurious behaviors (Forster, 2017) and unable to form connections even with family, while high-functioning individuals could have developed verbal communication and advanced cognitive

abilities (Ozonoff, Pennington & Rogers, 1991), with repetitive and limited interests (Lord et al, 2012). Symptoms most often appear in infancy or early childhood (Barbaro, & Dissanayake, 2009). However, individuals experiencing limited social demands early in life, or compensatory behaviors from family and caregivers and lack of awareness of family may be diagnosed later in life with ASD (Gold, 2017).

Background. In the United States, 1 in 59, or 1.7% children were identified with ASD, according to the 2014 estimates by the Centers for Disease Control and Prevention (CDC) Autism and Developmental Disabilities Monitoring Network (ADDM) (Baio et al., 2018). This network is an active surveillance system in the United States, made up by 11 monitoring sites, and hence this estimate is not representative of autism in the US population, and is an underestimation. Latest estimates of autism prevalence are higher than those from previous years, (Baio et al., 2018) i.e an estimated 1 in 150 individuals (0.66%) in 2002 and 1 in 68 (1.5%) in 2012 (Baio et al., 2018). This reveals that an increasing number of children are being diagnosed with ASD, and co-occurring with this rise is a greater need for early detection, diagnosis and treatment of ASD along with other developmental disorders (Bryson, Rogers and Fombonne, 2003). Research has shown that the major reasons for increasing prevalence of ASD are due to i) more children being diagnosed at a younger age, ii) an increasing number of children with milder symptoms are being diagnosed as having ASD, iii) ASD has been since re-categorized to include disorders which we previously termed pervasive developmental disorder NOS (not otherwise specified) and Asperger's disorder and iv) increasing public awareness and knowledge about the disorder (Boyd et al., 2010). Even with an increased awareness about ASD, the age of diagnosis averages at 4.7 years in the United States (Baio et al., 2018). It is also observed that majority of the children are not identified until close to 3 years of age, and hence,

there is very limited research on which interventions are efficacious for infants and toddlers at-risk of ASD. However, research conducted among preschoolers can provide a basic guideline of the type of interventions which work best.

Etiology of ASD

Non-modifiable risk factors for ASD and delayed diagnosis. Autism is a neurobehavioral disorder, which occurs due to a variety of genetic and environmental factors. The phenotypic heterogeneity of ASD makes understanding the underlying etiology of ASD difficult (Ronald et al., 2006). Population level studies have revealed multifactorial inheritance of ASD and multiple genes have been linked to the ASD phenotype (Schaefer & Mendelsohn, 2013). Genetic predisposition plays a role in ASD, as learned through twin studies; among monozygotic twins; if one twin has ASD the other has a 36 – 95% of developing the disorder, compared to 0 - 31% chance of disorder development in dizygotic twins (Muhle, Trentacoste & Rapin, 2004). One of the types of genetic associations that have been observed in ASD include familial aggregation, i.e. autism is more common among siblings of those affected by it (Folstein & Piven, 1991). If parents have one child diagnosed with ASD, there is a 2-18% chance of the second child being also affected (Ozonoff et al., 2011).

However, as mentioned previously, the dramatic increase in the prevalence of autism cannot largely be controlled and explained through genetics alone; epigenetics, or environmental disturbances on gene regulation also appears to have a role, such as by silencing of genes linked to ASD (Currenti, 2010). Environmental factors including low postnatal folic acid supplementation and maternal vitamin D insufficiency play a role in development of the autistic phenotype (Currenti, 2009). Environmental exposure of heavy metals, such as mercury, has also been associated with autism (Bernard et al., 2002; Kern et al., 2012). Hence, there is evidence for

the role that genetic predisposition and environment play in causing ASD. The interplay of genetics and the environment are both non-modifiable risk factors.

Another non-modifiable risk factor in development of autism is gender. ASD is 4 times more prevalent in males than females (Baio et al., 2018), a ratio which has remained relatively stable over time. Research on this phenomenon has revealed that this may be due to structural differences in the male and female brain, and also why females diagnosed with ASD appear to have brains more structurally similar in cortical thickness to their male counterparts (Jacquemont et al., 2014). There is also evidence of the protective effect of estrogen for ASD, also called the “female protective model” and greater mutational burden, which explains lower rates of autism among female population due to the fact that a greater number of mutations are required for females to develop autism than males (Jacquemont et al., 2014).

Modifiable Risk factors for ASD and diagnosis. At a biological level, there is no cure or conventional medical treatment for ASD. However, individuals that are at-risk of developing ASD, or those already diagnosed can receive services that can help improve life outcomes for individuals (Bryson, Rogers and Fombonne, 2003). Currently, the focus on dealing with ASD and its effects isn't prevention of the disorder, but early detection of ASD, and the implementation thereafter of appropriate therapy services for individuals as soon as possible. Delayed diagnosis and delayed provision of therapy services occur due to several factors, which are systematically modifiable.

While gender itself is a non-modifiable risk factor in the development of ASD, the male to female ratio of 4:1 in ASD can also be explained by a diagnostic bias to a certain extent; females diagnosed with ASD tend to have more severe symptoms of autism than males (Loomes, Hull & Mandy, 2017). This could mean two things; i) females are more likely to have a more

severe phenotype of ASD across majority of cases, or ii) females with more severe ASD symptoms are more likely to be diagnosed (Loomes, Hull & Mandy, 2017).

Ethnic variations are observed in the actual and diagnostic prevalence of ASD in the United States; non-Hispanic White children have been found to be 30% more likely to be identified with ASD than non-Hispanic Black, and 50% more likely than Hispanic children (Zaroff & Uhm, 2012); individuals of Hispanic descent have the lowest prevalence of ASD, while Whites tend to have the highest prevalence (Zaroff & Uhm, 2012). These numbers may be due to the structural and diagnostic differences among these populations. When the same population was tested for intellectual disability, out of those classified as intellectually disabled, 48% were non-Hispanic black children, 38% Hispanic children and 25% non-Hispanic white children (ADDM, 2012).

Early Detection, Diagnosis and Intervention. For individuals at-risk of having ASD, an earlier age of diagnosis is linked to better long-term outcomes, as the sooner the child is diagnosed with ASD and/or other developmental delay/disorder, the earlier relevant support services can be implemented for the individual child (Johnson and Meyers, 2007). *Early intervention (EI) services*, are support and services available to babies and young children with developmental delays and disabilities, as well as their families. EI services for children with ASD include a combination of interventions that are behavioral, medical and educational in nature (Boyd et al., 2010). Some of the most common therapies accessed by parents of children with or at-risk for ASD include speech-language pathology, applied behavior analysis (ABA) therapy, occupational therapy and sensory integration, physical therapy services, as well as medications for comorbid conditions (Bradshaw, Steiner, Gengoux & Koegel, 2015). For those children showing symptoms of ASD, or those considered to be “at-risk” for an ASD diagnosis,

early intervention can start as early as 2 years of age (Koegel, et al., 2014). Intensive behavioral and developmental interventions, for children with ASDs are often the most common type of early intervention services received. Utilization of Early Intervention Services for children with ASD is supported by research that has shown that early intensive intervention can decrease the severity of autistic characteristics and symptoms, increase IQ and improve communications skills and behavior over time (Howlin et al., 2009; Landa, 2018).

It is vital to intervene as early as possible, as the first two years of infant's development are marked by rapid growth of cognitive, language and social abilities (Carpenter et al., 1998) and the second year of life is when an exponential increase in verbal communication abilities occurs (Paul, 2007). With the current average age of diagnosis being 4.7 years in the United States, by the time children are diagnosed with ASD and intervention begins, their social communicative abilities compared to their typically developing peers are already very underdeveloped (Shattuck et al., 2009). The first two years mark the critical period in a child's development where accelerated brain growth occurs (Wolff et al., 2012), along with language acquisition (Kuhl, 2010), and social development (Dawson, 2008); after which cortical brain growth slows down, and without intervention during this critical time, deficits in social attention and communication may continue to persist as ASD symptoms (Chevallier et al., 2012).

Efficacy of Early Intervention. A study on the utilization of a comprehensive developmental and behavioral intervention known as the Early Start Denver Model (ESDM) revealed that EI services among preschool-aged children at-risk of ASD can result in significant improvements in IQ, adaptive behavior, and decrease severity of ASD diagnosis compared to those referred to other community services (Dawson et al., 2010). A follow-up study after the ESDM interventions had ended found these improvements were due to the long-term alteration

of children's brains towards a normalized developmental trajectory as a result of early intensive service grounded in increased social affect and engagement (Dawson et al., 2012; Estes et al., 2015).

Several studies have shown that beginning high quality autism-specialized intervention services in infancy that feature i) parent involvement and ongoing parent coaching, ii) individualization to infant's developmental profile, iii) greater intensity and duration of intervention as soon as diagnosis has occurred and iv) a broad focus of learning targets can significantly improve cognitive and adaptive functioning for children with ASD compared to those that did not receive such services early on (Wallace & Rogers, 2010). Overall, empirical research supports the conclusion that evidence-based early intervention services, grounded in applied behavior analysis (ABA) principles (Roanne, Fisher and Carr, 2016; Virués-Ortega, 2010) are generally more effective in improving language development, cognition and adaptive behavior skills than other standard services provided to the individual (Magiati, Tay and Howlin, 2012). This reveals the importance of utilizing Early Intervention services for those children at-risk of developing ASD.

Autism as a public health problem. ASD are now considered an emerging public health issue on a global scale. More recently, the Global burden disease (GBD) initiative found that before the age of 5, ASDs were the leading cause of years lived with a disability (YLDs) followed by conduct disorder and ADHD (Baxter et al., 2015). ASD prevalence has increased over the years, as has the need for behavioral, medical, residential and other services required for diagnosed individuals (Leigh et al., 2016). Costs for ASD can be classified into direct medical, direct non-medical and indirect productivity costs, with the largest chunk of costs being direct non-medical (Leigh & Du, 2015). The estimated economic burden for autism spectrum disorders

was \$268 billion for 2015, and the projected future cost for ASD by 2025 are estimated to be around \$461 billion, ranging from \$276 – \$1011 billion in the United States (Leigh & Du, 2015). By 2025, with the increasing ASD prevalence and increasing population in the US, ASD related costs will range from 0.982 to 3.600% of the total GDP expenditure (Leigh & Du, 2015). The 2025 cost estimates for ASD will far exceed the cost for some of the more chronic diseases including stroke, hypertension and diabetes (Go et al., 2014).

Hence, it is important to focus future research efforts into finding cost-efficient treatments and therapies, that can help reduce the overall economic burden of ASD on future generations by improving the functioning of persons with ASD. Currently, it has been found that intense early intervention therapy over a 3-year period can be more effective than special education services provided over an 18-year period, where the timeliness of the stage at which early intervention is provided is vital for greater independence of the child diagnosed with ASD (Chasson, Harris & Neely, 2007). Programs which focused on making the individual more independent are more cost-effective than standard-care or day services (Mavranouzouli et al., 2014); the earlier the therapy services start, the better developmental and life outcomes overall can be expected (Reichow B., 2012). ASD currently has no cure and will continue to affect diagnosed individuals throughout their lifespan (Bölte, 2014). With this understanding of burden of disease, it is important to further research the burden of disease for ASDs to inform future public health policy, so that appropriate and timely interventions can be implemented to reduce future burden of disease.

Underutilization of Early Intervention. One of the determining factors of utilization of early intervention services is the age of ASD diagnosis and whether it was received before 3 years. The earlier ASD is diagnosed in individuals, the quicker empirically effective therapies

can be incorporated within a child's treatment plan with the expectation of improved long-term outcomes across social skills, communication and overall quality of life (Shattuck et al., 2009).

While several studies have looked at factors associated with delayed detection of ASD and how that delays important services including Early Intervention, to date no studies have researched the factors directly associated with utilization of early intervention services.

Understanding Delayed Diagnosis of ASD. There are several critical elements to timely identification of ASD followed by implementation of early intervention services, including parent concerns about child's development, the parent's diagnostic experiences and provider response to their concerns (Keenan et al., 2010). Even though the American Academy of Pediatrics recommends routine screening for ASD starting at 18 months (Johnson & Meyers, 2007), these practices are not being implemented in reality. While most caregivers report that the child can be seen demonstrating symptoms of ASD in the first two years of a child's life, the average age of diagnosis for ASD in the United States is 4 years (Baio, et al., 2018). The diagnostic features used to conclude whether an individual has ASD or not are present fairly early on, and research has shown that individuals can very reliably be diagnosed with ASD by 24 months of age, a diagnosis that is highly likely to persist until 36 months of age, with social and communication deficits presenting as the earliest indicators of ASD (Woods and Wetherby, 2003). Families have reported that even after expressing their concerns about their child's symptoms to a pediatrician by 18 months of age, they were unsuccessful in getting the help they needed on the path to diagnosis and intervention in a timely manner (Marshall et al., 2016). A delay in what can potentially be diagnosed earlier can then expectedly result in underutilization of early intervention services.

Race and Ethnicity. Racial and ethnic disparities are a major contributor for the overall delayed age of ASD diagnosis in the United States. While there is an overall late diagnostic age for children with autism, regardless of their ethnic background, an even greater delay exists in the diagnosis of children from ethnic minorities (Valicenti-McDermott et al., 2012). ASD is under-diagnosed in lower income communities and non-Caucasian populations (Dickerson et al., 2016). In 2009, a study on racial/ethnic disparities in the identification of children with ASD found that African-American, Hispanic and children of other non-white race/ethnicity were less likely than White children to have documented ASD, and those from non-white ethnicities who did get diagnosed with ASD had more severe cases of ASD and an average IQ score of 70 or lower (Mandell et al., 2009.)

Role of parental concern. Parental concerns about their child's development play an important role in timely diagnosis of ASD and the decision-making process about their child's treatment and referral to services (Herbert & Kouglouglioti, 2010). Studies on specific parental factors associated with early identification of ASD have found evidence of the impact of factors including previous experience with raising children, knowledge of typical child development, cultural differences in expectations of typical child development, parent education level and age, which then impacts implementation and utilization of appropriate EI services (Marshall et al., 2016). Parent beliefs and interpretation regarding etiology for any disease can impact treatment related decisions; for ASD, parents in some cultures believe their child's condition is temporary and that the child will grow out of it, while others who have concerns developmental concerns early on believe in the lifelong nature of ASD and that it is largely genetic (Marshall et al., 2016). However, there is very limited research on the nature of parental concern, and which

specific concerns around a child's development are most likely to encourage the parent to seek professional help and EI services.

Role of providers. The role of health care and primary care providers is critical in helping or delaying early diagnosis of ASD and follow-up referral to services. One study found that even when controlled for the age of child at parent's initial concern regarding their child's development, parents of children with ASDs were more likely to receive a passive response from their healthcare provider about their child's developmental concern than those that had some other intellectual disability and/or developmental delay (Zuckerman, Lindly and Sinche, 2015); those children that did receive an ASD diagnosis had shorter delays in diagnosis when the primary care provider (PCP) responded proactively to concerned parents. In a focus group conducted with parents of children with ASD, it was found that parents found their PCP to have limited time for interaction with their child's PCP and that they felt they could not openly talk about their concerns (Marshall et al., 2016); PCPs also did not follow up parental concerns with appropriate referral. While these findings emphasize the importance of primary care providers for a timely diagnosis of ASD, further research is needed to better understand the role of PCPs, other health care provider and non-providers including teachers on the utilization of early intervention services.

Individuals with Disabilities Education Act (IDEA).

In the United States, IDEA is a law that authorizes funding to different states and educational institutions, agencies and non-profit organizations to assist individuals with disabilities. The Individuals with Disabilities Education Act (IDEA) ensures that all children with disabilities are eligible to free, appropriate public education to meet their unique needs and to prepare them for further education, employment and independent living. Before IDEA was

implemented, over 4 million children with disabilities in the United States were denied appropriate access to public education (U.S Department of Education, 2010). This act was initially enacted in 1975 to ensure appropriate services and education for children with disabilities and has since then been revised multiple times. There are four parts included in this statute, and Part C of IDEA includes information regarding formula grants that can help assist states in providing appropriate evidence-based EI services for infants and toddlers from birth through age two (Turnbull, Huerta & Stowe, 2004) that are experiencing, either a developmental delay or have been diagnosed with a physical or mental condition that increases the probability of having a developmental delay (Adams & Tapia, 2013). It is important to note that these services are provided at no cost to the families and caregivers of individuals with disabilities, hence affordability of services is not implicated in underutilization of EI.

Limitations of previous studies.

As mentioned above, while previous studies have researched factors associated with a delayed diagnosis of ASD, and the importance of Early Intervention services in improving developmental outcomes for individuals, no studies have determined which factors that might have a direct association with utilization of Early Intervention Services among those at-risk for ASD.

Study overview

To our knowledge, no one has examined the direct association of age of diagnosis on utilization of Early Intervention Services, the role and nature of parental concerns about a child's development, their diagnostic experience, the role of health care professionals and insurance related factors in utilization of EI services for those diagnose with ASD. Hence, in order to fill this gap in literature, this study will find answers to the following research questions: Among those with ASD, which factors best predict whether Early Intervention services were used or not? We further analyzed to see: A) Is there an association between age of initial ASD diagnosis and utilization of EI services? B) Is there an association between parental concerns and EI? If so, which ones? C) Is there a difference between the parent diagnostic experiences of those who received EI services compared to those that did not? D) Is type of insurance and perception of types of services covered play a role in Early Intervention? The hypotheses for the research questions are: A) Age of initial diagnosis is associated with EI; B) Age of initial parent concerns about child's development and nature of concerns is different between those that received EI vs. those that did not; C) There is a difference between the diagnostic experiences of those parents whose children received EI vs. those that did not; and D) Insurance coverage is not associated with Early Intervention.

The following specific aims will be examined to address the research questions and hypotheses stated above:

- Specific aim 1: Determine whether younger age of ASD diagnosis is positively associated with EI.
- Specific aim 2a: Determine whether age of first parent concerns is positively associated with EI.

- Specific aim 2b: Determine the developmental concerns of parents that increase likelihood of EI.
- Specific Aim 3: Determine whether response from physician/healthcare provider to developmental concerns is associated with EI.
- Specific Aim 4: Determine whether parent's perception of insurance coverage associated with EI.

Methods

This study utilizes a secondary data analysis of the 2011 Survey of Pathways to Diagnosis and Services (“Pathways Survey”), which is a nationally representative, parent-reported survey for children ever diagnosed with ASD and/or intellectual disability (ID) and/or developmental delay (DD). This survey was sponsored by the National Institutes of Mental Health (NIMH) and the survey conducted and organized by the Centers for Disease Control and Prevention National Center for Health Statistics (NCHS) and is held in the Data Resource Center archives (DRC, 2011). The 2011 Pathways survey was conducted as a follow-up to the 2009/10 National Survey of Children with Special health care needs (NS-CSHCN). Within the pool of parents/guardians that had completed the NS-CSHCN, the parents who had reported that their child was ever diagnosed with one or more conditions of ASD, ID and/or DD were re-contacted to complete the Pathways Survey (DRC, 2011).

Study participants.

The participants for the survey were parents or guardians that had originally completed the 2009 NS-CSHCN survey. Participants (n= 4032) were deemed eligible to complete this survey if they met the following criteria: 1) the parent who responded and agreed to complete the follow-up 2011 survey was the same parent who had originally completed the 2009 survey; 2) the child whose parent was being surveyed was between 6 – 17 years old at the time of 2011 survey; 3) child still lived in the same household; and 4) respondent reported in the 2009 interview that child had ever had ASD, ID and/or DD (DRC, 2011). Of the 4032 parents/guardians who completed the Pathways survey, we selected out cases by using ‘Yes’ responses to the question asked of all respondents “Has a doctor or other health care provider ever told you that your child had Autism, Asperger’s Disorder, pervasive developmental

disorder, or other autism spectrum disorder?”. This yielded a sample size (n=1765), which is the population of those whose child had ever been told/diagnosed with ASD or other related conditions. Within this sample, the data were separated out by the outcome variable of interest ‘Early Intervention’ (Yes/No); of those ever diagnosed with ASD, n=639 responded with Yes to child ever receiving EI, while n= 1126 responded with No to child ever receiving EI.

Study design.

All study procedures were approved by the California State University, San Marcos Institutional Review Board. Participants of the Pathways Survey provided informed consent before beginning the survey and were free to omit responses from any questions they did not wish to answer and were informed they could end the survey at any time.

Data analysis.

The statistical test used to determine if an association between independent variables across the categories relevant to our research questions and specific aims and dependent variable of Early Intervention existed was a Pearson Chi-squared analysis. This test was to determine association between independent variables and EI, which were both categorical or dichotomous. In cases where the independent variables were categorized into 3 or more categories, dummy variables were created to run an effective Chi-squared analysis.

Spearman correlation was used to assess if the any independent variables were highly correlated with one another, with a correlation coefficient of 0.7 or greater being determined as a highly correlated pair of variables. In such a case, the variable with the least difference in percentage across EI was not used for the regression analysis to avoid multi-collinearity between independent variables. P-values, β -coefficients and odds-ratios were obtained using a binary

logistic regression, which were conducted in order to establish which independent variables best predicted EI in the population ever diagnosed with ASD.

All presented P-values were two tailed; $p \leq 0.05$ was considered statistically significant.

Data were analyzed using SPSS (version 25.0; IBM corp., Armonk, NY).

Results

Organizing results

The purpose of this study was to answer the following proposed research questions: Among those with ASD, which factors best predict whether Early Intervention services were used or not? We further analyzed to see: A) Is there an association between age of initial ASD diagnosis and utilization of EI services? B) Is there an association between parental concerns and EI? If so, which ones? C) Is there a difference between the parent diagnostic experiences of those who received EI services compared to those that did not? D) Is type of insurance and perception of types of services covered play a role in Early Intervention?

We originally hypothesized that A) Age of initial diagnosis is associated with EI; B) Age of initial parent concerns about child's development and nature of concerns is different between those that received EI vs. those that did not; C) There is a difference between the diagnostic experiences of those parents whose children received EI vs. those that did not; and D) Insurance coverage is not associated with Early Intervention.

To answer the research questions and test these hypotheses, the following specific aims were examined: (1) Determine whether younger age of ASD diagnosis is positively associated with EI; (2a) Determine whether age of first parent concerns is positively associated with EI; (2b) Determine the developmental concerns of parents that increase likelihood of EI; (3) Determine whether response from physician/healthcare provider to developmental concerns is associated with EI, and; (4): Determine whether parent's perception of insurance coverage associated with EI.

This study showed many significant results. Most prominently, age of the child at the time when parents first spoke to a health care provider about their developmental concerns,

followed by age of first developmental concerns and then age of initial ASD diagnosis were best predictors of EI. Other predictors of EI were ethnicity, a co-occurring diagnosis with Intellectual disability or mental retardation, and parental concerns about child's development within the social/communication domain and motor/coordination issues.

Presenting Results

(Table 1) shows the sample characteristics of those children ever diagnosed with ASD, with results from a Chi-squared test of dependent variables and the independent variable of whether or not child received EI services. The total n= 1765, where majority of the sample have an age of diagnosis of over 3 years (n=1461 or 82.7%); this is significantly related to utilization of EI services as those below the age of 3 were more likely to receive EI. The ratio between males to females within the sample is 4:1, as expected, and is not significantly associated with EI. Ethnicity is associated with EI, such that a greater percent of White, non-Hispanic individuals did not receive EI (78.2%), than those that did (67.8%), while a greater percent of Hispanic (12.8% vs 9.2%), Other-non-Hispanic (10.3% vs 7.3%) and Black, Non-Hispanic (9.1% vs 5.2%) reported as having utilized EI compared to those that did not.

All regions of residence in the US (except for the Southern states) are significantly associated with EI; individuals in the North-east were more likely to get EI, than those in the Mid-west or the West. Parent education and household income were not associated with EI services; majority of parents are high school graduates or higher (84.9%). If the child was insured, he/she was more likely to receive EI, ($p= 0.003$), with the combination of public, or public and private insurance coverage increasing likelihood for EI.

Table 2 is an in depth look at the role of other conditions, age of parents' first concerns and age at first diagnosis as well as eligibility status for EI services. Coexisting conditions of ID

and/or DD while having an ASD diagnosis at the time of the survey increased likelihood of the child receiving EI services; within the ASD diagnosis, only if the diagnosis was labelled as ‘pervasive development disorder’ or ‘autistic disorder’ (more severe ASD diagnosis on the spectrum) did the likelihood for a child to get EI increase. We also observed that if the parent first had concerns about child’s development, specifically at or before birth up to 23 months, the child was more likely to get EI.

Parental concerns largely existed across three domains: social/communication, general behavioral issues and motor coordination issues. A higher percentage of children got EI if the parent(s) were concerned that child talked later than usual, didn’t respond to sounds or when called, was not talking at all, or if the speech skills that had already developed were lost, child did not talk as well as children of same age and lacked eye contact when interacting with others (Table 3). follow-up action to those concerns to utilization of EI services and determines which specific developmental concerns are significantly associated with EI services. Parent discussing observed concerns with a doctor or healthcare provider and/or a school professional is associated with utilization of EI services. Age of first concerns is also significantly associated ($p < 0.000$) such that concerns before age of 3 made it more likely for child to get EI.

Problem behaviors (such as wandering, tantrums, aggression and destructive behavior), difficulty learning new skills and being “in their own world” were all significantly associated with utilization of EI services but did not necessarily mean that child would be more likely to get EI (Table 3).

A doctor or health professional’s referral of parent to specialist or a response of “too early to tell” in response to parent concerns both were associated with increased percentage of those getting EI (Table 3).

Differences were observed in parent diagnostic experiences between those that got EI compared to those that did not. A child was more likely to get EI if a specialist pediatrician such as a developmental pediatrician or a neurologist first informed parent about a possible developmental disability/ASD, and also if the parent was told the same by an additional health professional, and if that professional was also a specialist doctor, a pediatrician, neurologist or some other professional besides the ones the parent was asked about at time of survey (Table 4).

Within the insurance coverage domain, it was seen that a fewer percentage of children received EI if the parent had the perception that the treatments, services or service providers that the child needed was not covered by their health insurance (Table 5); however, no significant differences were seen between those children whose insurance covered behavior management, psychological, speech language and/or occupational therapy services.

Finally, EI among this sample was best predicted by the age when parent had developmental concerns about child, spoke with a school professional, health professional and/or if an ASD diagnosis was made before the age of 2 years, if the child was from an ethnic minority, if the parents were ever told the child also had either an intellectual disability (ID) or mental retardation, and if the parent was concerned largely about their child's social/communication problems, specifically if they did not respond to sounds or when called, and if the child also had gross motor coordination problems; ethnicity was also a significant predictor of EI (Figure 2).

If the age of initial diagnosis was before the age of 3, the likelihood for EI increased by 360%. If the parents discussed concerns with a school professional, a health care provider, or if they had developmental concerns after the age of 2, this decreased the likelihood of EI by 49%, 47% and 57% respectively. An additional diagnosis of an Intellectual Disability or mental

retardation increased the likelihood of EI by 74%. Within the type of concern, issues with gross motor skills and within the social/communication domain, specifically not responding to sounds increased likelihood of EI by 72% and 66% respectively. Ethnicity was also a significant predictor, White, non-Hispanic individuals were 40% less likely to get EI than the rest of the ethnic minority groups. (Figure 2).

Discussion

This study is the first to ever take such an in depth look at which factors across the domains of age, parent concerns, diagnostic experiences, role of provider and insurance are associated with EI and best predicted this outcome variable. We found that age of 2 years or below is critical when talking about Early Intervention; earlier is better. It is vital that parents that do have concerns about their child's development discuss these concerns with a professional before the age of 2 (Table 1, Figure 2). We also found a surprising association between ethnicity and EI for the ASD condition; being from a White, non-Hispanic background reduced the likelihood of EI. The literature shows that White individuals are more likely to be diagnosed with ASD, and also have higher rates of a documented ASD, however, it seems that there is a gap in getting a diagnosis and getting appropriate EI services, which suggests that even in the White group there is an underutilization of EI services.

Insurance was also associated with EI; being insured through a public or public and private provider increased likelihood of EI compared to just private or other insurance; it seems that this might be dependent on the understanding/perception the parent has of the services that might be covered for their child; if the parent perceived insurance would not cover EI services, the child is less likely to get EI.

A secondary diagnosis/or another condition that was responsible for a child's deficits was found among those that had a higher percentage of EI (Table 2), specifically an ID diagnosis. This data was from a 2011 survey, when ASD was still categorized within terms including Pervasive developmental disorder, Autistic disorder and Asperger's disorder. It appears that when a more severe diagnosis was made, the child was more likely to receive EI.

It was surprising to see that behavioral difficulties were not a major parent concern and did not increase the percentage of those that received EI. While individuals with ASD do have behavioral difficulties and deficits, it might be possible that since these appear later of in childhood, they might not be predictive of EI, which occurs before the age of 3. Also, many parents might believe that the child might grow out of those behaviors, or that behaviors might be a disciplinary problem, and not related to an underlying disability. It appears that the most concerning symptom for a parent to get help and discuss concerns are if the parent did not respond to sounds, which falls under the social/communication domain (Table 3, Figure 2). This was also seen in other study among school aged children, where parents reported that they were most concerned about deficits in their child's social interaction (28%), followed by problem behavior (26%) and then academics (18%) (Azad & Mandell, 2016).

It was seen that a higher percentage of children received EI if the parent was involved in the decision-making process during follow-up with a health professional and was aware when a developmental screening was conducted or had filled out a questionnaire about child's developmental concern. This sheds light on importance of parent involvement during the time while a child is in process of receiving a diagnosis, and this can be significantly related to if the parent will follow-up to get EI for his/her child.

It is important to note that consulting a developmental pediatrician or a neurologist was significant in increasing likelihood of EI compared to other professionals. Previous studies on parent experiences while getting a diagnosis for their child, parents have reported feeling like they could not discuss concerns about child's development with the professional as the provider did not share a similar sense of urgency about the child's development and that the parent felt there was never enough time during a doctor's visit to discuss their concerns. It is common

practice for developmental screenings to be conducted during well-child checkups at 18 and 24 months; however, there is a possibility that screenings specific for ASD, using the M-CHAT (Kuban et al., 2009) tool are not being conducted as early as developmental concerns are raised, even when the M-CHAT can reliably determine newborns being at-risk for ASD.

Limitations

While we did find an association of region of residence with EI, it would be interesting to utilize state-level data to understand how IDEA is implemented in different states and what some of the challenges are for states to possibly receive funding and provide EI. Another limitation of the data is that all interviews were conducted in English, which introduces a bias as the survey automatically excluded any non-English speaking individuals. About (80%) of the parents were mothers of the child, followed by fathers (19%) and other guardians (1%). Majority of parents had graduated with a high school degree or more; while parent education level was not significantly associated with EI, it would be interesting to look how different tiers of education level (including college education or higher) predicted EI.

Strengths

This study allowed for preliminary look into predictors of EI, which has not been looked at before. A large sample size and data that is nationally representative provided results which have more external validity. This study has provided a better understanding of the most important factors for EI and has laid the groundwork for future studies to delve into the different domains and get a better understanding of the policies and practices that will increase utilization of EI services available by the state to its residents.

Implications for Future Research

Based on the results, we can stress the importance of universal screening to detect ASD early on. When looking at parent concerns and parent-related factors, it is important to increase parent knowledge of atypical child development, and the early signs of ASD. The gap in EI suggests a problem of access to services; as per IDEA, these services are available to all those diagnoses with a disability or developmental delay without any cost to the family, however these services are still underutilized among all ethnic groups. Parents might need to education about availability of these services as well, which can be done right at birth when other conditions are being tested for. However, it is also important to further understand systemic bias in underutilization of services and address where these gaps exist.

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Tables

Table 1: Sample characteristics of those ever identified as having Autism Spectrum Disorder, Asperger's Disorder or Pervasive Developmental Disorder, National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC), Survey of Pathways to Diagnosis and Services, 2011, n = 1765.

Characteristics	Total ASD		Early Intervention				Chi-sq P-value
	(n = 1765)		Yes (n = 639)		No (n = 1126)		
	n	%	n	%	n	%	
Age at official ASD diagnosis							0.000
3 – 17 years	1350	82.8	378	64.2	972	93.4	
0 – 2.9 years	280	17.2	211	35.8	69	6.6	
Gender							0.288
Male	1391	78.8	498	78.1	893	79.3	
Female	373	21.1	140	21.9	233	20.7	
Ethnicity							
White, non-Hispanic	1314	74.4	433	67.8	881	78.2	0.000
Other, non-Hispanic	186	10.5	82	12.8	104	9.2	0.012
Hispanic	148	8.4	66	10.3	82	7.3	0.017
Black, non-Hispanic	117	6.6	58	9.1	59	5.2	0.002
Parent Poverty Level (Income level of CSHCN's household) % Federal poverty level (FPL)							
0 - 99% FPL	257	14.6	104	16.3	153	13.6	0.140
100% - 199% FPL	344	19.5	123	19.2	221	19.6	0.901
200% - 399% FPL	582	33.0	201	31.5	381	33.8	0.317
400% FPL or greater	582	33.0	211	33.0	371	32.9	1.000
Residence							
Northeast	350	19.8	175	27.4	175	15.5	0.000
Midwest	406	23.0	130	20.3	276	24.5	0.046
South	488	27.6	173	27.1	315	28.0	0.699
West	521	29.5	161	25.2	361	32.0	0.003
Highest Parent Education in Household							0.580
More than High School graduate	1499	84.9	547	85.6	952	84.6	
Less than or equal to High School graduate	266	15.1	92	14.4	174	15.5	
Insurance							0.003
Child is insured	1712	97.1	630	98.6	1082	96.2	

Characteristics	Total ASD		Early Intervention				Chi-sq P-value
Child is uninsured	52	2.9	9	1.4	43	3.8	
Type of Insurance Coverage at Interview							
Private	924	52.4	294	46.0	630	56.0	0.000
Public	472	26.8	191	29.9	281	25.0	0.025
Both Private and Public	268	15.2	133	20.8	135	12.0	0.000
Other comprehensive insurance	48	2.7	12	1.9	36	3.2	0.127
Uninsured	52	2.9	9	1.4	43	3.8	0.003

Table 2: Early Intervention and association with other conditions, NCHS of the CDC, Survey of Pathways to Diagnosis and Services, 2011, n = 1765*.

Sample of parents that were ever told child had autism, Asperger's disorder, pervasive developmental disorder, or other autism spectrum disorder**	Early Intervention				Chi-sq. P-value
	n = 1765				
	Yes		No		
	n	%	n	%	
	n=639		n=1126		
Parent ever told child had:					
Developmental delay (DD)	529	82.8	720	63.9	0.000
ADD/ADHD	291	45.5	659	58.5	0.000
Intellectual disability (ID) or mental retardation	249	39.0	200	17.8	0.000
Pervasive Development Disorder (PDD)	329	57.9	400	39.4	0.000
Autistic Disorder	349	60.8	452	43.9	0.000
Asperger's Disorder	168	28.6	560	53.9	0.000
Age Parent first told child had ASD					0.000
3.0 - 17 years	381	59.2	977	86.5	
0 - 2.9 years	211	35.6	69	6.6	
Parents first concerned about child's development at:					
1-23 months	370	57.9	255	22.6	0.000
24-47 months	155	24.3	464	41.2	0.000
Condition of concern at or before birth	82	12.8	65	5.8	0.000
48+ months	21	3.3	310	27.5	0.000
Parent ever told child was:					
Ineligible for Early Intervention (Y/N)	50	7.8	99	8.8	0.533
Ineligible due to level of function	26	4.1	52	4.6	0.631
Other	22	3.4	33	2.9	0.570

*Missing, skipped, refused and "don't know" responses are included in the "NO" column under Early intervention.

**Variables only include 'yes' responses, and exclude 'no', 'don't know', missing or skipped responses.

Table 3: Early Intervention and Association with Parental Concerns around child's development, National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC), Survey of Pathways to Diagnosis and Services, 2011, n = 1765.

Parental Concerns**	Early Intervention*				Chi-sq P-value
	n = 1765				
	Yes		No		
	n=639		n= 1126		
	n	%	n	%	
Child's Age when:					
First Development concerns					0.000
0 - 35 months	432	74.2	348	32.9	
2 years +	150	25.8	709	67.1	
Parent(s) first talked to health care provider about concerns					0.000
0 - 35 months	438	73.1	315	31.3	
2 years +	161	26.9	691	68.7	
Parent(s) first talked to a teacher, school nurse, school counsellor, or other school professional about concerns					0.000
0-35 months	131	23.0	56	5.4	
2 years +	438	68.5	972	86.3	
Action taken by Parents (Y/N):					
Talked to a doctor or health care provider about concerns	601	94.1	1011	89.8	0.002
Spoke with a teacher, school nurse, school counsellor, or other school professional	570	89.2	1032	91.7	0.104
Type of Developmental Concern					
Social/Communication Problems (Y/N)- child:					
Talked later than usual	354	55.4	494	43.9	0.000
Didn't respond to sounds or when called	325	50.9	403	35.8	0.000
Was not talking at all	252	39.4	233	20.7	0.000
Had difficulty playing or interacting with others, or played alone "in [his/her] own world"	296	46.3	734	65.2	0.000
Some speech skills that [he/she] had already developed were lost	201	31.5	238	21.1	0.000
Did not talk as well as other children of same age	355	55.6	544	48.3	0.003
Lacked eye contact when talking or playing with others	359	56.2	597	53.0	0.214
Didn't seem to understand what parent or other adults said to [him/her]	257	40.2	470	41.7	0.546
Didn't seem to understand nonverbal communication, such as tone of voice, facial expressions or other body language cues	336	52.6	594	52.8	0.960
General Behavioral Issues- child:					

Parental Concerns**	Early Intervention*				Chi-sq P-value
Had behavioral difficulties such as sleeping or eating problems, high activity level, wandering, tantrums, aggressive or destructive behavior	338	52.9	725	64.4	0.000
Insisted on sameness or had difficulties with change	251	39.3	692	61.4	0.000
Had unusual gestures or movements (hand-flapping, toe-walking, or self-spinning)	219	34.3	397	35.3	0.716
Motor/coordination Issues- Child:					
Had problems with coordination or gross motor skills	285	44.6	398	35.3	0.000
Had problems with fine motor skills	213	33.3	523	46.4	0.000
Other – Child had:					
Medical problems (i.e. seizures, lack of physical growth, stomach problems)	150	23.5	196	17.4	0.002
Difficulty learning new skills	246	38.5	509	45.2	0.007
Difficulty learning new things (the alphabet or numbers)	184	28.8	342	30.4	0.516
Doctor or healthcare provider’s response to your concern:					
Made a referral to a specialist (such as developmental pediatrician, child psychologist, occupational or speech therapist)	391	61.2	539	47.9	0.000
Suggested that the parent discuss the concern with school	138	21.6	355	31.5	0.000
Said it was too early to tell if anything is wrong	252	39.4	377	33.5	0.013
Conducted developmental tests	287	44.9	461	40.9	0.109
Said that the child might “grow out of it”	258	40.4	465	41.3	0.725
Other (verbatim response)	145	22.7	269	23.9	0.599
Said nothing was wrong/the behavior was normal	158	24.7	292	25.9	0.609
Parent Involvement – Doctor:					
Told parent that they were carrying out a developmental screening or assessment of child	333	52.1	437	38.8	0.000
Had parent fill out a questionnaire about specific concerns about child’s development, communication, or social behaviors	256	40.1	398	35.3	0.051
If parent filled out a questionnaire, it asked about:					
Concerns or observations regarding how child talks or makes speech sounds	148	23.2	68	6.0	0.000
Child’s interaction with parent or others	145	22.7	72	6.4	0.000
Parent concerns or observations about how child behaves and gets along with others	93	14.6	301	26.7	0.000
Parent concerns or observations about words and phrases child uses and understands	83	13.0	237	21.0	0.000

*Missing, skipped, refused and “don’t know” responses are included in the “NO” column under Early intervention.

**Variables only include ‘yes’ responses, and exclude ‘no’, ‘don’t know’, missing or skipped responses.

Table 4: Early Intervention and Parent Diagnostic Experiences, National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC), Survey of Pathways to Diagnosis and Services, 2011, n = 1765.

Parent Diagnostic Experiences**	Early Intervention*				Chi-sq P-value
	Total n = 1765				
	Yes		No		
	n=639		n= 1126		
	n	%	n	%	
Type of doctor or other health care provider first told parent that child had autism or ASD					
Other psychologist (non-school)	106	16.6	222	19.7	0.112
A specialist pediatrician such as a developmental pediatrician	93	14.6	99	8.8	0.000
Pediatrician or other general health care provider	88	13.8	124	11.0	0.094
Neurologist	68	10.6	83	7.4	0.021
Other	67	10.5	108	9.6	0.562
Psychiatrist	50	7.8	178	15.8	0.000
A specialist doctor (other than developmental pediatrician psychiatrist, or neurologist)	37	5.8	58	5.2	0.584
Team of professionals/multidisciplinary team	25	3.9	43	3.8	0.899
Physical, occupational, speech or other therapist	22	3.4	23	2.0	0.084
School psychologist/counsellor	17	2.7	71	6.3	0.001
Another type of general health care provider	12	1.9	29	2.6	0.413
Told by any other doctor, health care provider, or school professional that child had autism or ASD	348	54.5	554	49.2	0.032
Types of other doctors, health care providers, or school professionals:					
School psychologist/counsellor	78	12.2	134	11.9	0.844
Teacher	68	10.6	123	10.9	0.859
Pediatrician or other general health care provider	66	10.3	83	7.4	0.031
Other	64	10	78	6.9	0.022
Other psychologist (non-school)	63	3.6	109	9.7	0.898
psychiatrist	46	7.2	77	6.8	0.771
A specialist pediatrician such as a developmental pediatrician	44	6.9	42	3.7	0.003
neurologist	37	5.8	27	2.4	0.000
A specialist doctor (other than developmental pediatrician psychiatrist, or neurologist)	34	5.3	39	3.5	0.059
Another type of general health care provider	17	2.7	25	2.2	0.558
School nurse	5	0.8	9	0.8	0.971

**Missing, skipped, refused and “don’t know” responses are included in the “NO” column under Early intervention.*

***Variables only include ‘yes’ responses, and exclude ‘no’, ‘don’t know’, missing or skipped responses.*

Table 5: Early Intervention and Parent Perception of Unmet Insurance needs, NCHS of the CDC, Survey of Pathways to Diagnosis and Services, 2011, n = 1765*.

<u>HEALTH CARE SERVICES**</u>	Early Intervention*				Chi-sq P-value
	Total n = 1765				
	Yes		No		
	n=639		n= 1126		
	n	%	n	%	
<u>UNMET NEEDS AND INSURANCE ADEQUACY</u>					
Treatments, services, or service providers that child needs are not covered by health insurance (Y/N)	382	61.8	717	68.5	0.006
Treatments, services, or service providers covered by health insurance					
Behavioral Management Services	576	93.5	995	95.8	0.049
Psychological Services	576	93.5	995	95.8	0.753
Speech or language	577	93.7	986	94.9	0.318
Occupational Therapy	579	94.0	996	95.9	0.097

*Missing, skipped, refused and “don’t know” responses are included in the “NO” column under Early intervention.

**Variables only include ‘yes’ responses, and exclude ‘no’, ‘don’t know’, missing or skipped responses.

Figure 1: Output with adjusted R²

Model Summary			
Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	1285.446 ^a	.253	.348

a. Estimation terminated at iteration number 5 because parameter estimates changed by less than .001.

Figure 2: Binary logistic regression analysis of factors that best predict utilization of early intervention services within the ASD population, NCHS of the CDC, Survey of Pathways to Diagnosis and Services, 2011, n = 1765.

		Variables in the Equation							
		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for EXP(B)	
								Lower	Upper
Step 1 ^a	Age at Initial ASD Diagnosis	1.297	.187	48.222	1	.000	3.657	2.536	5.273
	Age when parent first discussed concerns with health care provider	-.640	.195	10.803	1	.001	.527	.360	.772
	Age when parent first talked to a school professional	-.684	.213	10.299	1	.001	.504	.332	.766
	Age of First Development Concerns	-.835	.195	18.310	1	.000	.434	.296	.636
	Intellectual Disability or Mental Retardation	.552	.159	12.006	1	.001	1.737	1.271	2.375
	Problems with coordination – gross motor skills	.540	.141	14.712	1	.000	1.716	1.302	2.262
	Didn't respond to sounds or when called	.509	.139	13.372	1	.000	1.664	1.266	2.186
	Ethnicity	-.521	.155	11.382	1	.001	.594	.439	.804
	Constant	2.370	.458	26.839	1	.000	10.700		

a. Variable(s) entered on step 1: Age at Initial ASD Diagnosis, Age when parent first discussed concerns with health care provider, Age when parent first talked to a school professional, Age of First Development Concerns, Intellectual Disability or Mental Retardation, Problems with coordination – gross motor skills, Didn't respond to sounds or when called, Ethnicity.