FACTORS THAT INFLUENCE AGE OF IDENTIFICATION OF CHILDREN WITH

AUTISM AND PERVASIVE DEVELOPMENTAL DISORDER NOS

A Dissertation Presented to the
Faculty of the College of Education
University of Houston

In Partial Fulfillment
of the Requirements for the Degree

Doctor of Philosophy

by

Chana R. Adelman

August 2010

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Finally, special thanks to my loving husband who has supported and encouraged me to achieve my goals.

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Abstract

Early diagnosis of autism spectrum disorders (ASD) is crucial because early identification can lead to early intervention, which has been shown to improve the outcome of children diagnosed with ASD. This study explored the current mean age of diagnosis of Autism and Pervasive Developmental Disorder, NOS in the United States. Analysis of variance was employed to determine whether average age of diagnosis of children with Autism and Pervasive Developmental Disorder NOS differs in the four regions in the United States. Linear regression analyses were performed to determine which of the following factors predict age of diagnosis: the child's ethnicity, whether the child has an older typically developing sibling, whether the child has an older sibling who had/has a developmental delay other than autism, whether the child has an older sibling who has been diagnosed with autism, whether the child was first diagnosed with another disorder, the type of first symptoms to cause concern, whether the child was referred to ECI, whether the child switched pediatricians, whether the child's pediatrician conducted regular developmental screenings, whether the child's pediatrician conducted a screening specific to autism, reaction of pediatrician if parent raised concerns regarding child's development, whether the child was covered by health insurance, annual household income, and parents' level of education.

Potential participants were recruited with the assistance of the Interactive Autism Network (IAN) Research Database at the Kennedy Krieger Institute and Johns Hopkins Medicine in Baltimore, sponsored by the Autism Speaks Foundation.   Participants were selected from a pool of participants who have registered with IAN, who have agreed to participate in autism research, and whose children met the study criteria. The potential participants were sent a recruitment letter via email by IAN research personnel, which included a link to the on-line survey. The study description and a link to the survey were also posted on the IAN Community Research Opportunities Bulletin Board.

A sample size of 654 participants was used for data analysis. Current age of diagnosis in months of autistic disorder and PDD-NOS in the United States was 37.78, and SD=16.269. Due to violations of normality assumptions for age of diagnosis, a logarithm transformation was used (M=1.54 and SD=.166). Results of a one-way ANOVA indicated differences in age of diagnosis among the four regions in the United States F (3, 650) = 7.618, p=.01).   Tukey's post hoc comparisons of the groups indicated that the mean log base 10 age of diagnosis in the Midwest (M=1.59) was significantly later than in the Northeast (M=1.5152, p=.000) and South (M=1.5219, p=.000). Results of a Pearson Correlation indicated a significant negative correlation (r=-.409, n=654, p=.000) between date of birth and age of diagnosis, with later birthdays being associated with lower age of diagnosis.   Regression results were statistically significant, F(25, 620)=7.549, p<.001, R^2=.233. Having autistic older sibling/s, being

referred to ECI, and having a pediatrician who performed an in-depth screening in response to parent concerns, were negatively correlated with the logarithm of age of diagnosis, while having first symptoms of non-autism specific behavioral difficulties, being given a non-ASD diagnosis prior to ASD diagnosis and switching pediatricians during first five years of life, were positively correlated with the logarithm of age of diagnosis.

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Chapter I

Introduction

According to the Diagnostic and Statistical Manual of Mental Disorders (4th

ed., text rev. [*DSM-IV-TR];* American Psychiatric Association, 2000) autism

spectrum disorders (ASD) are lifelong developmental disorders characterized by

social, communication and behavioral problems, which are present before three

years of age. Between the years 1991 and 1997 there was an astonishing 556%

reported increase in the prevalence of pediatric autism, making it more common

than childhood cancer, spina bifida, and Down syndrome (Muhle, Trentacoste, &

Rapin, 2004).

The increase in the prevalence of ASD has resulted in increased

awareness of the symptoms associated with ASD and has generated

considerable research in the area of early identification of ASD. Early diagnosis

of autism is crucial for several reasons, but most importantly, because early

identification can lead to early intervention, which has been shown to improve the

outcome of children diagnosed with ASD (Bristol-Power & Spinella, 1999; Eaves

& Ho, 2004; Freeman & Cronin, 2002; Moore & Goodson, 2003; Stone et al.,

1999; Woods & Wetherby, 2003). This study focuses on whether research in the

area of early identification of ASD has impacted age of diagnosis in clinical

practice and what factors predict early identification of ASD?

Chapter II

Review of Related Literature

Literature Review

Prevalence of Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) are more common than previously thought and are now a major public health issue (Dosreis, Weiner, Johnson, & Newschaffer, 2006). According to the Centers for Disease Control and Prevention, 1 in 150 children in the U.S. have an ASD (Centers for Disease Control and Prevention, government report, retrieved September 4, 2007). Autism Spectrum Disorders include the Pervasive Developmental Disorders that are delineated in the DSM-IV-TR, namely Autism, Asperger's Disorder, and Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS), which is sometimes referred to as "atypical autism." Rett's Disorder and Childhood Disintegrative Disorder are nonautistic pervasive developmental disorders (Volkmar and Klin, 2005).

Proposed Practices for Diagnosing Autism

In 1999, a consensus panel led by the Child Neurology Society and American Academy of Neurology and representing nine professional organizations, including the American Psychological Association, proposed practice parameters for the diagnosis and evaluation of autism (Filipek et al., 1999). According to their parameters, screening for autism calls for two different levels of investigation, each addressing different questions. Level 1 screening should be performed on all children by their pediatrician at their well-visit check-ups. When

a child passes the Level 1 screening they are rescreened at their next well-visit. If the child fails or does not demonstrate key developmental milestones, laboratory tests such as a formal audiological assessment and lead screening are recommended along with a specific screening for autism. If a child does not pass the Level 1 autism screening, he/she is referred to Early Intervention or the local school district and proceeds to Level 2, which is specific to the diagnosis and evaluation of autism (Filipek et al.).

In 2001, the American Academy of Pediatrics (AAP), Committee on Children with Disabilities published a position paper delineating the role of the pediatrician in the diagnosis and treatment of children with ASD. The paper recommended that pediatricians listen carefully to parents when discussing the child's development, being especially vigilant when there are deficits in language and social skill development. The AAP also recommended that extra attention should be given to siblings of children diagnosed with ASD. In 2007, the AAP published a new policy report which charges all pediatricians to engage in both ongoing surveillance of young children and autism specific screenings at 18-months and 24-months of age (Johnson & Myers, 2007). Pediatricians with adequate training and experience diagnosing ASD are encouraged to utilize autism-specific diagnostic tools to make a definitive diagnosis. If the primary care physician is uncomfortable diagnosing ASD he/she should promptly refer the child to a specialist or a team of specialists with expertise in this area (American Academy of Pediatrics, 2001; Johnson & Myers, 2007). This is especially important because research has shown that parents who perceived that there was a long

delay in obtaining a diagnosis for their child tended to have less confidence in their child's physician (Harrington, Patrick, Edwards, & Brand, 2006). Ultimately, pediatricians may serve as the "medical home" for children with ASD by referring them to appropriate specialists (audiologists, speech-language pathologists, psychologists, genetic counselors), to appropriate interventionists (early intervention, school-based special education) and by referring parents to appropriate education and support groups (American Academy of Pediatrics, Committee on Children with Disabilities, 2001).

It should, however, be noted that "the earlier diagnosis the better" is not a universally shared opinion. In the conclusion of their recently published paper, Matson, Wilkins, and Gonzalez (2008) delineate the possible problems with diagnosing too early. They posit that there is no magic cutoff time for early identification, as development occurs in spurts and varies from child to child. Since the reliability and specificity of ASD diagnoses increases until a child is at least 3 to 4 years of age, Matson et al. suggest that it may make more sense to wait until more accurate diagnosis is possible.

Current Practices in the Identification of Autism Spectrum Disorders

Despite the practice parameters for diagnosing autism proposed by the consensus panel in 1999 (Filipek et al., 1999) and the position paper published by the AAP in 2001, the educational and medical sectors may lack a systematic early identification system for ASD. According to Dosreis et al. (2006), evidence of increases in autism special education eligibility during the elementary school years suggests that Child Find programs are not identifying all children with ASD.

However, increased awareness and better diagnostic tools has resulted in some decrease in the average age of diagnosis (Rutter, 2006).

Screening

A screening is a brief assessment designed to identify those in need of more comprehensive evaluations. Screenings differ from diagnostic measures in that they typically take less time to administer, do not require as much training and expertise to administer and indicate level of risk for disability as opposed to the presence of a disability (Coonrod & Stone, 2005). Filipek et al. (1999) recommend that general Level 1 screenings be performed on all children, by their pediatricians, at their well-visit check-ups. The goal of the Level 1 screenings is to identify any children at risk of atypical development. The Ages and Stages Questionnaire, Second Edition (ASQ; Squires, Bricker, & Potter, 1997), The BRIGANCE Screens (Glascoe, 1996), The Child Developmental Inventories (CDIs; Ireton & Glascoe, 1995), and The Parents' Evaluation of Developmental Status (PEDS; Glascoe, 1998) are all Level 1 screening instruments that take a few minutes to complete and are easily administered in the pediatrician's office.

Autism specific screening instruments can be divided into two levels. Level 1 screeners are used to identify children at-risk for ASD in the general population and are most likely to be used by primary care physicians. These screeners tend to be brief since they are administered to a large number of individuals, most of whom who are not at risk of ASD. Level 2 screeners are typically more time consuming, but are only used with select individuals who are already considered to be at risk. These screeners are usually administered by professionals other

than primary care physicians. Some screeners can be used at both Level 1 and at Level 2 (Robins & Dumont-Mathieu, 2006).

According to Robins and Dumont-Mathieu (2006) autism specific Level 1 screeners for young children include the Checklist for Autism in Toddlers (CHAT; Baron-Cohen, Allen, & Gillberg, 1992), the Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, & Barton, 1999), and the Pervasive Developmental Disorders Screening Test, Second Edition (PDDST-II; Siegel, 2004). The MCHAT and the PDDST-II have been developed to also be used as Level 2 screeners, and the Screening Tool for Autism in Two-Year-Olds (STAT; Stone, Coonrod, & Ousley, 2000) is to be used only as a Level 2 screener. The more recently developed Developmental Behaviour Checklist: Early Screen (DBC-ES; Gray & Tonge 2005), would likely also be considered a Level 2 screener as it screens for autism in young children with developmental disabilities (Gray, Tonge, Sweeney, & Einfeld, 2008).

The CHAT has been reliably used as a screening tool for children with autism who are 18 months of age (Coonrod & Stone, 2005; Filipek, et al., 1999; Freeman & Cronin, 2002). It is designed to be administered at routine healthcare visits and consists of both parent report and interaction items. The MCHAT is a parent report screener that consists of the nine parent report items of the CHAT as well as additional items that determine the presence of symptoms associated with autism. Use of this screener is recommended for children at age 24 months (Coonrod & Stone). Use of the MCHAT has been attempted with children as young as 16 months of age, but positive predictive power is much better when

used with children at least 24 months old (Pandey, Verbalis, Robins, Boorstein,

Klin, & Babitz, et al. 2008). The PDDST-II consists of 3 stages, each with

different clinical utility. The PDDST-II Stage 1 is a Level 1 screener that primary

care physicians can use with children between the ages of 12 and 48 months

(Robins & Dumont-Mathieu, 2006).

The Level 2 screeners are designed to differentiate children at risk for

autism from children who are at risk for other developmental disabilities (Coonrod

& Stone, 2005). The PDDST-II Stage 2 and the PDDST-II Stage 3 are designed

to be used as Level 2 screeners for children between 12 and 48 months of age.

The Stage 2 version is designed to be used in developmental clinics and the

intended use of the Stage 3 version is in autism-specific clinics (Robins &

Dumont-Mathieu, 2006). The STAT is an interactive measure that has shown to

be an effective Level 2 screening tool for children ages 24-35 months, who have

not received interventions (Coonrod & Stone; Freeman & Cronin, 2002; Stone,

Coonrod, & Ousley, 2000). Results of an exploratory study indicate that the

STAT may also have adequate screening properties for children as young as 14

months (Stone, McMahon, & Henderson, 2008). The DBC-ES is a 17 item

parent checklist which has not only been shown to screen for ASD, but also

provides a broad screening of behavioral and emotional problems in young

children (Gray, et al., 2008).

The Autism Behavior Checklist (ABC; Krug, Arick, & Almond, 1980),

Social Communication Questionnaire (SCQ; Rutter, Bailey, Berument,

LeCouteur, & Lord, 2003), Gilliam Autism Rating Scale (GARS; Gilliam, 1995)

and The Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1998) are all Level 2 screening measures that were not designed specifically for young children, but may have utility for this age group.

The ABC is a behavior rating scale that assesses functioning in five areas that are often impaired in individuals with autism. Its utility as a screener for young children is questionable, because its psychometric properties have not been studied in samples of young children (Coonrod & Stone, 2005). The SCQ is a parent-report questionnaire, based on the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994), which parents can complete independently. However, it can only be used for children ages four or older. It provides an efficient means of obtaining diagnostic information or screening for ASD. There are two versions of the SCQ, one that assesses current behavior and one that assesses lifetime behavior. The lifetime version is useful for diagnostic purposes, whereas, the current behavior version is appropriate for assessing change over time (Ozonoff, Goodlin-Jones, & Solomon, 2005). The GARS is an instrument typically completed by parents and is appropriate for rating the behavior of children ages 3 to 22. It is easy to use and the subscales correlate with the DSM-IV-TR symptoms for autism. Nevertheless, it has a high false negative rate, which may result in missed diagnoses when used by inexperienced practitioners (Ozonoff, et al.). The CARS is a structured observation instrument that consists of 15 items and is appropriate for use with children over 24 months old. The CARS total score is highly correlated with the ADI-R, but the former test over-identifies autism relative to the ADI-R,

occasionally classifying children with mental retardation as having autism. The CARS also does not measure constructs such as joint attention, which have been found to be important to the diagnosis of autism (Ozonoff, et al.).

Importance of early diagnosis

The emphasis on early identification is partly due to the fact that there is mounting evidence that demonstrates that developmental disruption in children with ASD is present prior to three years of age (Landa, 2008). There is overwhelming evidence indicating the efficacy of intensive early intervention for a considerable proportion of young children who are diagnosed with an ASD (Freeman & Cronin, 2002; Moore & Goodson, 2003; Woods & Wetherby, 2003). Early identification and treatment improves quality of life and enhanced opportunities for appropriate education and community independence (Bristol-Power & Spinella, 1999). Early intervention has been demonstrated to improve behavior, language, IQ scores, (Eaves & Ho, 2004; Stone et al., 1999) and social and adaptive behavior (Stone et al.).

Children who display impairments in the social and communication domains at age 2 will rarely outgrow these problems without intervention (Filipek et al., 1999; & Eaves & Ho, 2004). The critical period for the development of language which is delayed or disordered in children with ASD is between birth and 5 years of age (Downey, et al., 2002). Later age of parental recognition of symptoms has been found to be related to worse outcomes in social and communication functioning and poorer nonverbal cognitive skills (Chawarska, Paul, Klin, Hannigen, Dichtel, & Volkmar, 2007). Turner, Stone, Pozdol, and Coonrod 2006

conducted a follow-up study of children with autism at age nine, seven years after they were initially diagnosed. The students were divided into higher outcome, mixed outcome, and lower outcome groups based on their IQ and language scores at age nine.   Statistical analysis revealed that children in the higher outcome group were diagnosed younger, and had more total hours of speech and language therapy between the ages of two and three.

Intensive use of applied behavior analysis (ABA) can have considerable positive effects on the development of children who have an ASD. Studies show that children who received this type of treatment prior to 48 months of age were more likely to achieve an inclusive educational placement in regular education (Harris & Handleman, 2000). A controlled comparison study conducted in the United Kingdom compared the outcomes of preschool children with autism who received early intensive behavioral intervention to children with autism who received a form of publicly funded education.   At 12 and 24 months there were notable differences favoring the intervention group on measures of intelligence, language, daily living skills, and positive social skills (Remington, et al., 2007). Pivotal Response Training, which uses components of ABA has shown to result in positive outcomes for the child and the family. There are indications that 85-90% of children diagnosed with autism can learn to use verbal communication as their primary mode of communication when taught approaches that specifically incorporate pivotal response motivational techniques prior to age five (Koegel, Koegel, & Brookman, 2003).

Research has shown that families who have children with ASD want definitive answers to their questions about their child's diagnosis as early as possible (Filipek et al., 1999; & Moore & Goodson, 2003). The pre-diagnosis phase during which parents first begin to notice signs of ASD is often characterized by confusion as to the cause of the behavior. They often have feelings of self-blame and substantial stresses are placed on family relationships. Parents often experience frustrating delays before receiving the appropriate diagnosis and during this time they may be given false reassurances and incorrect or misleading diagnoses (Mansell & Morris, 2004). Parents are most satisfied with the diagnostic process when their child is diagnosed at a young age and when fewer professionals are involved in the diagnostic process (Goin-Kochel, Mackintosh, & Myers, 2006). Other advantages to early identification include earlier educational planning and treatment, provision of family supports and education, reduction of family stress and anguish, and delivery of appropriate medical care to the child (Filipek et al.).

Factors associated with the validity of early diagnosis

Differential Diagnosis

Diagnostic validity of ASD, in general, is impacted by the fact that there are no independent biological or psychological markers for ASD. Hence, differentiating autism from other disorders can be difficult. Classification systems for ASD rely upon clinical history, patterns of behavior, and psychological functioning. The line that separates ASD from other developmental disorders, psychiatric conditions, or eccentric normality is often nebulous, because ASD

share features with other disorders. A child may have autism and a comorbid associated condition, so the autism may go unrecognized. Conversely, autism may be the sole condition but the child may be misdiagnosed with an associated condition. Some of the disorders that are likely to cause diagnostic dilemmas in young children are: generalized mental retardation; developmental language disorders; developmental coordination disorder; attention deficit/hyperactivity disorder; deficits of attention, motor control, and perception; Tourette's Syndrome; hearing impairments; and visual impairments (Wing, 2005). A recent study found that only 43.8% of autistic children received an autism diagnosis on their first mental health visit, the most common diagnoses other than autism were ADHD (21.4%), followed by conduct-related disorders (12.1%), adjustment disorder (9.6%), and cognitive disorders (7.9%). African-American children were approximately twice as likely as other children to receive a diagnosis of conduct disorder (15.7% vs. 6.7%) (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007).

The DSM-IV-TR (American Psychiatric Association, 2000) gives some general guiding principles for differentiating autism from other forms of PDD. Both Rett's Disorder and Childhood Disintegrative Disorder have distinct features that differentiate them from autism. Children with Rett's demonstrate head growth deceleration and usually lose previously acquired purposeful hand skills. Children with Childhood Disintegrative Disorder demonstrate a severe and rapid loss of skills after at least two years of normal development. Children with autism usually demonstrate developmental abnormalities during their first year of life. Asperger's Disorder differs from autism in that children with Asperger's do not

have delays in early language development. The DSM-IV-TR also provides guidelines for differentiating autism from: childhood schizophrenia, selective mutism, expressive language disorder, mixed receptive-expressive language disorder, mental retardation, strereotypic movement disorder, and attention deficit/hyperactivity disorder.

Validity of early diagnosis

Diagnostic features of autism spectrum disorders should be evident in very young children, because they involve abilities that develop within the first years of life in typically developing children (Jensen & Sinclair, 2002; Woods & Wetherby, 2003). Diagnosis by an experienced clinician can usually be made by 20-30 months of age (Eaves & Ho, 2004; Jensen & Sinclair). According to Landa (2008), in some cases autism can be diagnosed in some children as young as 14 months, but the autism diagnosis may be unstable in up to a third of the children diagnosed prior to 30 months of age.   Due to individual variation in presentation and developmental course and the limitations in diagnostic tools for very young children, diagnosis of ASD in children younger than 18 months will remain difficult (Brian, Bryson, Garon, Roberts, Smith, & Szatmari, et al., 2008).

A policy report recently published by the American Academy of Pediatrics (Johnson & Myers, 2007) charges all pediatricians to engage in both surveillance and screening of young children. "Surveillance" refers to the ongoing process of identifying children who may be at risk for developmental delays. This should occur at every childhood preventative doctor's visit through: attending to parent's concerns, observing the child, interacting with the child, maintaining a

developmental history of the child, asking age specific questions, identifying the

child's risk factors, and documentation of findings. A standardized screening

should be conducted any time a parent raises concerns that may indicative of an

ASD and all children should be screened with an ASD specific screening tool at

18-months and 24-months of age.

Werner, Dawson, Osterling, and Dinno (2000) demonstrated that differences

between typically developing infants and infants with ASD can be detected as

early as 8-10 months of age, with the most salient between group difference

being failure to orient to name. Orienting to name is a salient feature, because it

involves the social and communication domains as well as attention, and so, it

involves almost all domains which are believed to be impaired in children with

ASD (Werner et al.). Delays in language development may predict certain

autistic features in young children (Eisenmajer et al., 1998) and children with

poor language development and/or global developmental delays are most likely

to present early on for diagnosis (Eaves & Ho, 2004; McConachie, Le Courteur,

& Honey, 2005).

Baranek (1999) used retrospective video analysis of sensory motor and social

behaviors in 9-12 month old children and found subtle symptoms of autism

present at this young age. First birthday videotapes of typically developing

children and children diagnosed with ASD were compared and differences were

found in the children's showing and pointing responses, failure to orient when

name was called, and failure to look at the face of another person (Palamo,

Belinchon, & Ozonoff, 2006; Werner, 2000).

Baranek, David, Poe, Stone and Watson (2006) demonstrated that sensory features can be used for early identification purposes. They used the Sensory Experiences Questionnaire (SEQ) with four clinical groups and one typically developing group of children ages 5-80 months. The children with autism presented with general sensory hyporesponsiveness in both nonsocial and social contexts, which differentiated them from comparison groups.

Many studies that demonstrate early differences between children with ASD and children without ASD rely on retrospective parent report and analysis of early videotapes. Retrospective studies are limited by the reporter's hindsight bias and do not allow for the exploration of developmental trajectories of children with ASD (Mitchell, et al., 2006; Szatmari, Zwaignbaum, & Bryson, 2004; Zwaigenbaum et al., 2007). The more recent, prospective studies allow for the collection of data longitudinally across different ages, which can improve understanding of developmental trajectories. These studies also foster awareness of the impact of early delays in one domain, such as orienting to name, on the subsequent development of another domain, such as language. Prospective studies use several high risk groups for ASD including; children with early signs of developmental delays, children at greater risk for ASD, due to medical conditions or genetic anomalies and most frequently, infants who have an older sibling diagnosed with ASD. The sibling group is used most often as they are arguably the most clearly defined high-risk group and of all the neuropsychiatric disorders autism is associated with the highest relative risk in siblings compared to the general population (Zwaigenbaum et al.).

Recent prospective studies involving siblings of children diagnosed with ASD have found differences between siblings later diagnosed with ASD, siblings not diagnosed with ASD, and low-risk controls (Zwaigenbaum et al., 2007). For example, at 12 months of age and at 18 months of age children subsequently diagnosed with ASD produced fewer gestures and understood fewer phrases. At 18 months they also showed delays in their comprehension of and production of single words. Siblings not diagnosed with ASD did not differ from control group subjects in the areas measured except that the sibling group used fewer play related gestures at 18 months (Mitchell et al., 2006). An additional, likely, early marker of developing autism is peculiar use of simple objects, mainly involving abnormal or prolonged visual exploration and spinning or turning objects while exploring them (Ozonoff, Macari, Young, Goldring, Thompson, & Rogers, 2008). In another prospective study, Loh et al. (2007) examined a variety of stereotypic movements and postures of siblings of children diagnosed with ASD and low risk controls. The groups did not differ significantly in most of the areas measured. The two areas in which the groups did differ were that at 12 months infants later diagnosed with ASD "arm waved" more frequently than the non-ASD siblings and the typical infants. Also, at 18 months both sibling groups (ASD and non-ASD) had more frequent "hand to ears" postures when compared to typically developing children.

Bryson et al. (2007) examined the development of nine infant siblings of children diagnosed with ASD. Their study demonstrated that signs of autism were more noticeable in the infants who showed a decrease in IQ scores

between 12 and 24 (and in one case by 36) months of age, compared to the

infants with autism who did not demonstrate decreases in IQ scores. All the

children showed impaired social-communicative development, and atypical

sensory and motor mannerisms and/or repetitive behaviors. To varying degrees,

the emergence of autism in all the children was associated with a distinctive

temperament profile typified by marked irritability, intolerance of intrusions,

proclivity to negative affect, and difficulties with regulation.

According to Kraijer and de Bildt (2005), until recently, autism was unnoticed

and went undiagnosed in a large number of individuals with mental retardation.

As a result these individuals with autism or PDD were not provided with the

appropriate treatment for ASD. Early identification of ASD can now be made for

children with mild to profound mental retardation, using instruments such as the

Scale of Pervasive Developmental Disorder in Mentally Retarded Persons (PDD-

MRS; Kraijer, 1997) or the Autism Diagnostic Observation Schedule-Generic

(ADOS-G; DiLavore, Lord, & Rutter, 1995; Lord et al., 1989) and the ADI-R (de

Bildt et al., 2004).

A study by Chawarska, Klin, Paul, and Volkmar (2007) demonstrated that the

ADOS-G is sensitive to classifying ASD in the second and third year of life. In

their study, however, the ADOS-G did not adequately discriminate between

specific types of ASD, such as autism and PDD, for this age group. A recent

multisite study led by Gotham et al. (2008) found that sensitivity to classifying

PDD-NOS in verbally fluent children younger than 5 was improved using a

revised ADOS algorithm. The revised algorithm includes two new domains,

Social Affect and Restricted Repetitive Behaviors, which are combined to form one score. The changes in the algorithm reflect the current research in autism diagnosis and are more consistent with DSM-IV diagnostic criteria (Gotham, Risi, Pickles, & Lord, 2007). However, using this new algorithm sensitivity to classifying PDD-NOS was decreased for children under 5 years of age who communicate using phrase speech (Gotham et al., 2008).

Long term reliability of early diagnosis

The diagnosis of autism at age 2 has been found to be stable for at least one year, with 88-100% of children remaining within the autism diagnostic spectrum (Stone, et al., 1999). In a study by Moore and Goodson (2003), children were initially evaluated at age 2 with a comprehensive evaluation and were reevaluated at age 4.5. Results of this study demonstrate that autism can be reliably diagnosed at age 2 and that this diagnosis is stable. Turner, Stone, Pozdol, and Coonrod (2006) examined the developmental outcomes of children initially diagnosed at age 2, and evaluated again 7 years following diagnosis. Their research found that 88% of children remained on the autism spectrum at the 7 year follow-up. In 1999, Stone et al. examined the reliability of diagnosis of autism and PDD-NOS prior to age 3. Results demonstrated that diagnosis of autism at age 2 was more stable than for PDD-NOS one year after children were diagnosed. Of the children diagnosed with autism, 72% retained this diagnosis, 24% improved and were diagnosed with PDD, and 4% were diagnosed with non-ASD diagnosis. Of the children initially diagnosed with PDD-NOS, 92% remained on the autism spectrum, but nearly half the children demonstrated

more severe symptoms and were subsequently diagnosed with autism.   This

study also demonstrated that agreement between clinicians for discrimination

between ASD versus no ASD was greater than specific discrimination between

autism and PDD-NOS in children younger than 3.

In a recent study by Kleinman, et al. (2008) 77 children were evaluated for

autism two times. The first evaluation was conducted at approximately two years

of age. They were evaluated a second time at approximately 4 years of age.

Clinical diagnoses assigned at age 2, based on the DSM-IV criteria, were found

to be stable in that 80% of the children remained on the autism spectrum.

Consistent with previous research the diagnosis of autistic disorder (85% of the

cases) was more stable than PDD-NOS (47% of the cases). A comparison was

made between the diagnostic stability of ASD diagnoses based on DSM-IV

criteria, the ADI-R, the ADOS, and the CARS. Diagnostic stability fell within

acceptable ranges for the DSM-IV (80%), the ADOS (83%), and the CARS

(76%). Diagnoses made with the ADI-R were found to be less stable, at 67% for

this age group. Overall, this study further supports the proposition that ASD

diagnoses made at age 2 are likely to persist.

Research by McConachie et al., (2005), indicates that it is more difficult to

make early reliable diagnoses for children with Asperger's Disorder. Children

with Asperger's Disorder, who have abilities in the average range, are likely to be

referred for diagnosis when they demonstrate abnormal repetitive behaviors.

The impact of these behaviors is likely to increase in the preschool years. Most

children will be identified for evaluation when they are introduced to the demands

of the educational setting and have reached an age when lack of friendships, circumscribed interests, poor adaptive behavior, and difficulties with pragmatic language become obvious through comparison to their peers. Therefore, in community referred samples, early identification of children with Asperger's is not typically to be expected.

Typical age of diagnosis in the U.S.

Despite the validity of autism diagnoses made at the age of 2, the age of diagnosis of this disorder for most children in the United States is not until 3 to 4 years of age (Filipek et al., 1999; Werner, et al., 2000; Woods & Wetherby, 2003) with many parents not receiving a definitive diagnosis until 4-4.5 years of age (Stone et al., 2000). Results of a study conducted in Pennsylvania in 2005 indicated that average age of diagnosis for children with autism is 3.1 years, 3.9 years for children with pervasive developmental disorder, not otherwise specified, and 7.2 for children diagnosed with Asperger's (Mandell, Novak, & Zubritsky, 2005). A study conducted with parents of children with ASD in New York and New Jersey found that the mean age for the diagnosis of autism was 34 months and 51 months for Aspergers. This study also found that diagnoses were made 16 and 21 months after parents first concerns were reported for autism and Asperger's, respectively (Harrington, Rosen, Garnecho, & Patrick, 2006). An international study consisting of 494 parents of children with autism, 377 of whom were from the United States, found that average age of diagnosis for autism was 3.4 years, 4.2 years for PDD-NOS, and 7.5 years for Asperger's (Goin-Kochel et al., 2006).

The majority of children identified as having an ASD demonstrate symptoms of the disorder within the first two years of life, with most parents reporting onset of symptoms between 16 and 20 months of age (Woods & Wetherby, 2003). On average, most parents of children with ASD recognize that their children are experiencing problems around 18 (Landa, 2008) or 19 months of age (Chawarska et al., 2007a).

Despite the development of several screening and diagnostic instruments with acceptable psychometric properties that can be used with very young children, research indicates that early identification of children in the U.S. is lagging and that there is great variability across states in the prevalence of children with autism special education eligibility (Dosreis et al., 2006). Mandell and Palmer (2005) explored the factors that account for the variability across states in the prevalence of children with the autism special education eligibility. They collected data from the U.S. Department of Education Office of Special Education and Rehabilitative Services to determine the prevalence of autism special education eligibility by state, education related spending, number of school based health centers, and children living in poverty and from the American Board of Pediatrics for information regarding the number of pediatricians in each state. State characteristics were then divided by tertiles (percentiles which divide a distribution into thirds) based on per-pupil education spending. That is, states were divided into three ascending groups, separately, for each characteristic measured. Some of the state characteristics measured were; spending per pupil, students in special education, number of school based

health centers per 1000 students, and number of pediatricians per 1000 children.

Results of the study indicated that the number of children with autism special

education eligibility is positively correlated with the state's education-related

spending, number of pediatricians in the area, and number of school based

health centers in the state. Table I demonstrates the percentage of each state's

population receiving special education services for an autism spectrum disorder.

The data are from the fall of 2005 and include students ages 6 through 21 (IDEA

government report, retrieved October 15, 2007).

Table 1.

Students ages 6 through 21 being served through IDEA as a percentage of population

State	Autism %	State	Autism %
Alabama	0.19	Montana	0.15
Alaska	0.22	Nebraska	0.21
Arizona	0.24	Nevada	0.25
Arkansas	0.23	New Hampshire	0.28
California	0.31	New Jersey	0.35
Colorado	0.13	New Mexico	0.11
Connecticut	0.37	New York	0.30
Delaware	0.28	North Carolina	0.30
District of Columbia	0.23	North Dakota	0.21
Florida	0.22	Ohio	0.30
Georgia	0.28	Oklahoma	0.18
Hawaii	0.30	Oregon	0.62
Idaho	0.25	Pennsylvania	0.31
Illinois	0.28	Rhode Island	0.36
Indiana	0.45	South Carolina	0.19
Iowa	0.19	South Dakota	0.24
Kansas	0.21	Tennessee	0.19
Kentucky	0.20	Texas	0.27
Louisiana	0.17	Utah	0.25
Maine	0.43	Vermont	0.24
Maryland	0.37	Virginia	0.31
Massachusetts	0.39	Washington	0.29
Michigan	0.37	West Virginia	0.19
Minnesota	0.66	Wisconsin	0.37
Mississippi	0.12	Wyoming	0.21
Missouri	0.29		
50 states and D.C.	**0.29**		

Impediments to early identification of autism spectrum disorders

Several factors have been identified as impediments to early identification of ASD. According to Filipek et al., (1999) lack of healthcare coverage and the fact that fewer than 30% of primary care physicians conduct routine screenings for autism have impeded early identification of ASD. Mandell et al., (2005) found that children who were referred to specialists by their pediatricians in response to parental concerns were diagnosed about 4 months earlier than children who were not referred to specialists. In a survey conducted by Dosreis et al. (2006) twenty percent of pediatricians indicated that if they thought a child had an ASD, they would adopt a watch and wait approach.

Dosreis et al. (2006) indicated that 82% of pediatricians who participated in the study routinely screened for developmental delays, yet only 8% indicated that they routinely screen for ASD. The most commonly occurring precipitating events for ASD screening included parental concern (90%), suspicion during routine exam (90%), and failure of the general screening (80%). This study found that 62% of pediatricians were unfamiliar with ASD screeners and 32% of pediatricians reported that they lack sufficient time to screen for ASD. Pediatricians are also more likely to refer children suspected of having an ASD to a clinical specialist as the age of the child increases. Mandell et al. (2005) found that children who had four or more primary care physicians prior to diagnosis were diagnosed about 6 months later than children who had one primary care provider.

Disparities in healthcare availability

Race, ethnicity, and socioeconomic status have all been shown to influence diagnoses in various areas of medicine (Broomfield & Dodd, 2004; Lantz et al., 2006; Longway, Johnson, Garwood, & Davis, 2000). In 2002, the Institute of Medicine Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care (Institute of Medicine, 2002) conducted a study which found that ethnic minorities receive lower quality healthcare than whites even when factors such as degree of insurance and ability to pay for care are held constant. Mandell, Listerud, Levy, & Pinto-Martin (2002) found that, on average, black children are diagnosed with autism 1.5 years later than their white counterparts. Mandell et al., 2007 found that African-American children had 2.6 times the odds of initially receiving a diagnosis other than autism compared with whites. African-American children ultimately diagnosed with autism were nearly 3 times more likely than white children to receive another diagnosis first (Mandell, et al., 2007). It is hypothesized that this disparity may be attributed to economic factors, (Mandell, et al., 2002; Mandell et al., 2007) differences in clinical presentations and parent behaviors, and differential treatment by clinicians (Mandell, et al., 2002). A recent study found that whites and blacks had comparable prevalence rates for autism however, the prevalence rates for Latinos was significantly lower. Being black or Latino was associated with decreased access to services (Liptak et al., 2008).

Higher levels of household income and parental education are associated with earlier diagnosis and overall greater satisfaction with the diagnostic process (Goin-Kochel et al., 2006). Mandell et al. (2005) found that children from "near

poor" households were diagnosed with autism .9 years later than children who resided in households with incomes >100% above the poverty level. Liptak et al. (2008) found the lowest preschool prevalence of autism among poor children. In this study being poor was also associated with decreased access to services although, having Medicaid or Children's Health Insurance Program was associated with better access to some services. Socio-economic factors have been shown to correlate with age of diagnosis outside the U.S., as well. A study conducted in Jamaica found that low socio-economic status was a significant factor related to delayed autism diagnosis (Samms-Vaughn & Franklyn-Banton, 2008).

Proposed Research Study

Purpose of the study

Early identification of autism is critical for numerous reasons, but most importantly because interventions that can improve the functioning of children with ASD may be more effective with younger children (Downey, et al., 2002 Freeman & Cronin, 2002; Harris & Handelman, 2000; Moore & Goodson, 2003; Turner, et al. 2006; Woods & Wetherby, 2003). By definition, onset of autism is prior to three years of age. Research has demonstrated that early identification is well within the realm of possibility for those children who are affected. Experienced clinicians can reliably diagnose autism in children age 2 or younger (Bristol-Power & Spinella, 1999; Eaves & Ho, 2004; Jensen & Sinclair, 2002; Moore & Goodson, 2003; Stone, et al., 1999). In addition, subtle symptoms of autism can be detected by 9-12 months of age (Baranek, 1999) with more

pronounced symptoms by 12-24 months (Bryson et al., 2007; Clifford et al., 2007; Mitchell, et al. 2006).

Despite increased knowledge about early signs of autism and efforts on the part of the medical community, diagnosis of autism for most children in the United States does not usually occur until at least three years of age (Filipek et al., 1999; Harrington et al., 2006; Mandell et al., 2005; Stone et al., 1999; Werner, et al., 2000; Woods & Wetherby, 2003) with a considerable lag time between initially reported onset of symptoms and actual diagnosis (Harrington et al.; Stone et al.; Woods & Wetherby).

Recently published studies (Harrington et al., 2006; Mandell et al., 2005) indicate that average age of diagnosis of autism is between three and four years; however, both of these studies were conducted in specific states in the Northeastern section of the US. No nationwide studies that have examined average age of diagnosis on a national level were able to be located. This study will determine average age of diagnosis across the United States, which can then serve as a baseline for future studies looking at whether efforts to reduce the average age of diagnosis are successful.

Second, recent research looking at age of diagnosis has been limited to specific geographic regions in the northeastern part of the U.S. (Harrington et al., 2006; Mandell et al., 2005). This study will examine whether there are geographic trends in age of diagnosis of children with Autism and Pervasive Developmental Disorder. These data will indicate whether improvements need to be made in age of diagnosis in a specific region and whether certain areas of the

country lag behind other areas in early diagnosis. This information could be crucial to policy makers and medical providers who are attempting to implement changes in diagnostic practices.

Third, this study will examine whether average age of diagnosis across the United States is decreasing. This information is useful in determining whether efforts to reduce age of diagnosis have been successful.

Fourth, although research studies have examined factors that impact age of diagnosis of autism these studies have explored either practices of pediatricians or ethnicity or socioeconomic factors. This study will use a comprehensive set of predictors that draws upon these three areas to determine which specific factors predict age of identification of ASD. These predictor variables are: the child's ethnicity, whether the child is first born, whether the child has an older typically developing sibling, whether the child has an older sibling who had/has a developmental delay other than autism, whether the child has an older sibling who has been diagnosed with autism, whether the child was first diagnosed with another disorder, the type of first symptoms to cause concern, whether the child was referred to ECI, whether the child switched pediatricians, whether the child's pediatrician conducted regular developmental screenings, whether the child's pediatrician conducted a screening specific to autism, reaction of pediatrician if parent raised concerns regarding child's development, whether the child was covered by health insurance, annual household income, and parents' level of education. Based on the aforementioned research studies it is hypothesized that being Caucasian, being

the younger sibling of a typically developing child, being a younger sibling of a child with a developmental delay other than autism, being a younger sibling of a child who has been diagnosed with an ASD, being referred to ECI, maintaining the same pediatrician during the first five years of life, using a pediatrician that conducts regular developmental screenings, using a pediatrician that conducts screenings specific to autism, being referred to a specialist by the pediatrician (when parents raised concerns regarding development), being covered by health insurance, greater household income, and higher level of parent education will predict early diagnosis.

If children with ASD are to be provided the recommended early interventions, they must be identified and diagnosed at the earliest age possible. In order to do so, we must first identify the factors that are impeding early diagnosis and address these factors so that all children with ASD can be diagnosed and treated early.

Research questions

1. What is the current age of diagnosis of Autism and Pervasive Developmental Disorder, NOS in the United States?

2. Are there geographic trends in age of diagnosis of children with Autism and Pervasive Developmental Disorder, NOS in the United States?

3. Is there a relationship between the child's current age and the age at which they were diagnosed?

4. Which of the following factors predict age of diagnosis: the child's ethnicity, whether the child is first born, whether the child has an older

typically developing sibling, whether the child has an older sibling who had/has a developmental delay other than autism, whether the child has an older sibling who has been diagnosed with autism, whether the child was first diagnosed with another disorder, the type of first symptoms to cause concern, whether the child was referred to ECI, whether the child switched pediatricians, whether the child's pediatrician conducted regular developmental screenings, whether the child's pediatrician conducted a screening specific to autism, reaction of pediatrician if parent raised concerns regarding child's development, whether the child was covered by health insurance, annual household income, and parents' level of education.

Chapter III

Method

Participants

Eligible participants included either parent of a child diagnosed with Autism or Pervasive Developmental Disorder, NOS.   Research indicates that age of emergence of symptoms and age of diagnosis of Asperger's Disorder is significantly different from that of other ASD and that it is difficult to make an early reliable diagnosis of Asperger's Disorder. Therefore, children with the diagnosis of Asperger's Disorder were not included in this study. To limit the impact increased awareness of autism and decreased age of diagnosis over the last decade, only children age 10 years 11 months and younger at the time of the data collection were included.

The study used a convenience or nonprobability sampling technique. The sample consisted of eligible parents who volunteered to participate in the study. Potential participants were recruited with the assistance of the Interactive Autism Network (IAN) Research Database at the Kennedy Krieger Institute and Johns Hopkins School of Medicine in Baltimore, sponsored by the Autism Speaks Foundation.   Participants consisted of those who have registered with IAN, who have agreed to participate in autism research, and whose child/ren meet/s the study criteria. The potential participants were sent a recruitment letter (see Appendix A) via email by IAN research personnel, which included a link to the on-line survey. The study and a link to the survey was also posted on the IAN Community Research Opportunities Bulletin Board.

A 20% response rate and 5% bounce rate (emails that bounce back) was anticipated by IAN. In this case 4,635 emails were sent to potential participants who met study criteria. The emails were sent out in alphabetical order by last name over a period of several days. A total of 210 emails bounced back, which was about 4.5% of the emails sent out. It is, therefore, assumed that 4,425 emails were received by potential participants. During the data collection period which lasted about six weeks, 936 surveys were started. This translated to a response rate of just over 21%. However, not all data from the 936 respondents were used to run the analyses. Twenty-three respondents were eliminated because they did not provide some of the essential information such as the child's date of birth or the child's current diagnosis. Five of the participants were excluded because they were either missing birthdays or the age of the child exceeded 10 years 11 months. Seven more participants were disqualified since they were diagnosed with an ASD outside the United States. An additional 40 respondents were eliminated from the data set since the child's current diagnosis was either an unknown form of autism or Asperger's disorder. The remaining sample size of 868 was further reduced, as all cases that were missing data in any of the categories used in any of the analyses were eliminated. The resulting sample size was 654. Table 2 provides descriptive information for the obtained sample.

All but two states (Vermont and Wyoming) were represented in the sample. For information regarding number of participants and percentage of participants per state, see Appendix C.

Table 2.

Characteristics of participants diagnosed with autism or PDD in the United States

Characteristics	Frequency	Percent
Gender		
Male	553	84.6
Female	101	15.4
Primary Ethnicity		
African American	16	2.4
Asian/Pacific Islander	6	.9
Caucasian	581	88.8
Hispanic	33	5.0
Native American	2	.3
Other	16	2.4
Has an older sibling		
Yes	369	56.4
No	285	43.6
Has a typically developing older sibling		
Yes	311	47.6
No	58	8.9
Not applicable	285	43.6
Has a developmentally delayed older sibling		
Yes	72	11.0
No	298	45.6
Not applicable	284	43.4
Has an autistic older sibling		
Yes	54	8.3
No	315	48.2
Not applicable	285	43.6
U.S. Region where child was diagnosed		
Northeast	154	23.5
Midwest	168	25.7
South	222	33.9
West	110	16.8
Current Diagnosis		
Autism	431	65.9
PDD-NOS	223	34.1
Given Other Diagnosis Prior to ASD Diagnosis		
Yes	423	64.7
No	231	35.3
Referred to ECI		
Yes	554	84.7
No	100	15.3
Switched Pediatricians		
Yes	373	57.0
No	281	43.0
Pediatrician Assess for Development		
Yes	505	77.2
No	142	21.7
Missing	7	1.1

Pediatrician Assess for Autism		
Yes	165	25.2
No	489	74.8
Reaction of Pediatrician to Concerns		
Performed in-depth screening	27	4.1
Referred to specialist	188	28.7
Encourage to "wait and see"	326	49.8
Other	91	13.9
Not applicable	22	3.4
Child Covered by Medical Insurance		
Entire time	617	94.3
Part of the time	31	4.7
No	6	.9
Annual Household Income		
Under $25,000	45	6.9
$25,000-$50,000	135	20.6
$50,001-$75,000	153	23.4
$75,001-$100,000	150	22.9
Over $100,000	171	26.1
Level of Father's Education		
Some High School	17	2.6
High School Diploma/GED	83	12.7
Some College/Vocational Training	213	32.6
Bachelor's Degree	177	27.1
More than a Bachelor's Degree	159	24.3
Missing	5	.8
Level of Mother's Education		
Some High School	3	.5
High School Diploma/GED	41	6.3
Some College/Vocational Training	229	35.0
Bachelor's Degree	198	30.3
More than a Bachelor's Degree	178	27.2
Missing	5	.8

Survey Description

The survey titled *Exploring Practices of Diagnosing Autism-Revised,*

developed by the researcher (see Appendix B) was constructed on the basis of

information gathered from a review of the related literature on factors that may

affect age of diagnosis of ASD. A similar survey, *Exploring Practices of*

Diagnosing Autism (also developed by the researcher) was used in a pilot study.

Additions and changes were made to the original survey based on results of the

pilot study, to better reflect the related research, and to make it more user-

friendly. The survey required about ten minutes to complete and consisted of 26

questions that were designed to address factors that may be related to age of diagnosis of autism. Questions about socio-demographics were also included in the survey as they have also been found to be related to age of diagnosis.

Procedures

Approval for data collection from the University of Houston Committee on Human Subjects was obtained prior to data collection. Approval from IAN was obtained prior to the dissemination of the recruitment letter.

The online survey through *Survey Monkey* consisted of an informed consent describing the confidential and voluntary nature of the study, purpose of the study, potential benefits and risks of participating in the study. Participants were made aware that the results of the study may be published in professional and scientific journals. Contact information for questions regarding the study was included for the primary researcher, faculty sponsor, and the University of Houston Committee for the Protection of Human Subjects. Access to the study was contingent upon agreeing to participate in the research.

Research Design/Data Analysis

Analyses were conducted utilizing the Statistical Package for the Social Sciences (SPSS) version 16.0. Average age of diagnosis in the United States is reported in months using descriptive statistics. Average age of diagnosis was computed for each of the four regions in the United States as defined by the U.S. Census Bureau (United States Census Bureau, government report, retrieved April 5, 2008). These four regions are: Northeast, Midwest, South, and West (see Appendix C for a listing of states included in each region).   A one-way

analysis of variance was computed to determine whether average age of diagnosis differs significantly between the regions. Post-hoc analyses were conducted to determine which regions were significantly different. A minimum sample size of 180 (45 per group) was needed for a medium effect size at Power = .80 for .05 level of significance (Cohen, 1992), and this was obtained.

A Pearson correlation was used to determine if there is a relationship between the child's age and the age of diagnosis. Date of birth in mm/dd/yyyy format was entered as one variable and age when diagnosed with ASD was entered as the other variable.

A multiple linear regression analysis was used to determine which factors best predict early diagnosis.   Many of the factors to be included in the analysis have multiple possible responses, with each choice considered as separate predictor. There were 25 predictor variables (24 categorical variables and 1 continuous variable) and so a minimum sample size of 375 was needed for this analysis, based on the minimum recommended 15 subjects per predictor for a reliable regression equation (Stevens, 2002, p143). The obtained sample exceeded this minimum recommendation.   The factors included in the analysis were: the child's primary ethnicity (African American, Asian/Pacific Islander, Hispanic, Native American, with Caucasian as the reference category), whether the child is first born, whether the child has an older typically developing sibling, whether the child has an older sibling who had/has a developmental delay other than autism, whether the child has an older sibling who has been diagnosed with autism, whether the child was first diagnosed with another disorder, type of first

symptoms to cause concern (speech/language delays, medical problems, lack of

social interest, non-autism specific behavioral difficulties, autistic-type behaviors,

lack of ability to live independently or happily, with other first symptoms as the

reference category), whether the child was referred to ECI, whether the child

switched pediatricians during the first five years of life, whether the child's doctor

conducted regular developmental screenings, whether the child's pediatrician

conducted a screening specific to autism, the reaction of the pediatrician if parent

raised concerns regarding development (performed more in depth screening,

referred child to a specialist, encourage a "wait and see" approach, with other

reaction serving as the reference category), whether the child was covered by

health insurance, annual household income (continuous variable), and parents'

level of education and parents' level of education (some high school [1], high

school diploma/GED [2], some college or vocational training [3], bachelor's

degree [4], more than a bachelor's degree [5]). Parents' level of education was

the mean of the father and mother's highest level of education. The mean level

of parents' education was then categorized into three groups: low (mean of 1-

2.5), middle (mean of 3-4), and high (mean of 4.5-5). Low and high level of

education were used as predictors in the analysis, with the middle level serving

as the reference category. In cases where only one parent's level of education

was provided, only that parent's level of education was used.

Chapter IV

Results

Preliminary Analysis

Results indicate that average age of diagnosis (in months) in the United

States was M=37.78, and SD=16.269 (n=654). However, the values were not

normally distributed (skewness=1.614, kurtosis=3.264) and Shapiro-Wilk

(sig.=.000) indicates a violation of the normality assumption. An examination of

the histogram and boxplot indicates that there are outliers that likely affected the

normality of the distribution. The outliers are likely genuine scores as age of

diagnosis of autism can vary greatly. A comparison of the mean (37.70) and the

5% trimmed mean (36.25) indicates that the outliers are having some influence

on the mean. The researcher, therefore, opted to transform this variable using a

log base-10 transformation (Cohen, Cohen, West, & Aiken, 2003). The

skewness (.441) and kurtosis (.111) fell within acceptable ranges and Shapiro-

Wilk (.000) indicates no violation of the normality assumption. The logarithm of

the variable "age of diagnosis" was used to run the analyses. For a comparison

of the probability plots of age of diagnosis of ASD with and without the logarithm

transformation, see Figure 1.

Figure 1.

Normal Probability Plots of Age of Diagnosis.

Normal Q-Q Plot of TotalAgeDxMonths

Normal Q-Q Plot of LogTotalAge
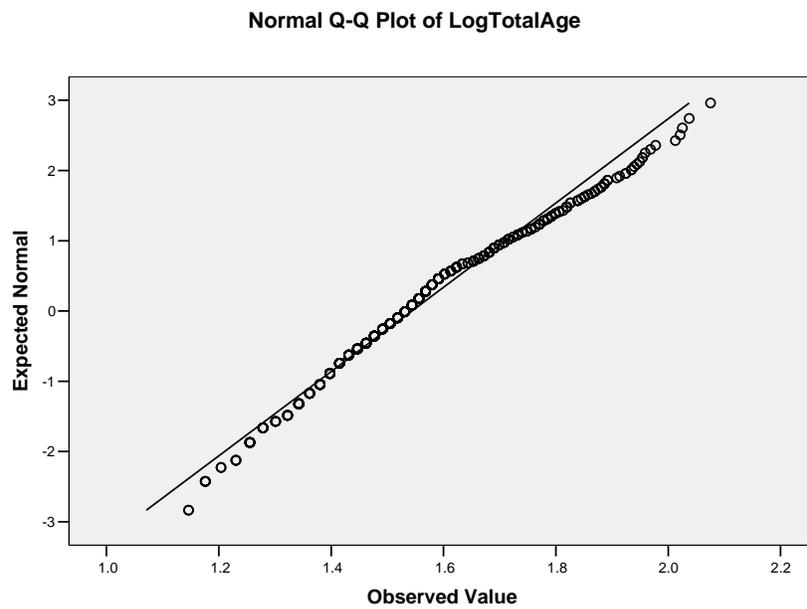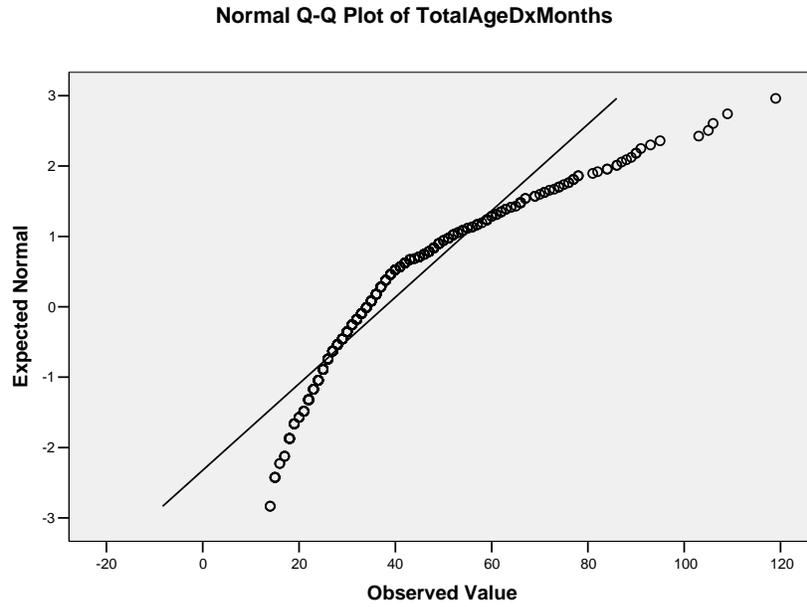
The Normal Q-Q Plot of TotalAgeDxMonths represents age of diagnosis, in months, prior to the logarithm transformation. The Normal Q-Q Plot of LogTotalAge represents age of diagnosis, in months, following the logarithm transformation.

Primary Analysis-Age of Diagnosis

As stated previously, the mean was used to determine current age of diagnosis of autistic disorder and PDD-NOS in the United States for the 654 participants. The log base 10 mean was1.54 (SD=.166).

Primary Analysis-Geographic Trends in Age of Diagnosis

A one-way ANOVA was used to test for differences in log base 10 age of diagnosis among the four regions in the United States. Mean age of diagnosis differed significantly across the regions, F (3, 650) = 7.618, p=.01). Despite reaching statistical significance, the actual difference in mean scores between the groups was relatively small. The effect size calculated using partial eta squared was .035. Tukey's post hoc comparisons of the groups indicate that the mean age of diagnosis in the Midwest (M=1.59) was significantly later than in the Northeast (M=1.5152, p=.000) and South (M=1.5219, p=.000). Comparisons between the remaining groups were not statistically significant. A summary of these results is presented in Table 3.

Table 3.

One-Way ANOVA results for impact of U.S. geographic region on age of diagnosis of ASD

Source	SS	df	MS	F	Partial eta^2
Between Groups	.616	3	.205	7.618***	.035
Within Groups (error)	17.512	650	.027		
Total	18.128	653			

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

Primary Analysis-Relationship between age of child and age of diagnosis

A Pearson Correlation was used to determine whether a relationship exists between a child's birthday and year   and age of diagnosis. There is a significant negative correlation (r=-.409, n=654, *p*=.000) between year and date of birth and age of diagnosis, with more recent birthdays being associated with earlier age of diagnosis.

Preliminary and Primary Analysis -Factors that predict age of diagnosis

Standard multiple linear regression was conducted with log base 10 age of diagnosis of ASD in months as the dependent variable and the child's primary ethnicity-African American, Asian/Pacific Islander, Hispanic, Native American (Caucasian as reference category); being a first born child; having an older typically developing sibling; having an older sibling who had/has a developmental delay other than autism; having an older sibling who has been diagnosed with autism; being diagnosed with another disorder before being diagnosed with an ASD; type of first symptoms to cause concern-speech/language delays, medical problems, lack of social interest, non-autism specific behavioral difficulties, autistic-type behaviors, lack of ability to live independently or happily (other first symptoms as reference category); having been given a non-ASD diagnosis prior to ASD diagnosis; being referred to ECI; having switched pediatricians during the first five years of life; having a doctor who conducted regular developmental screenings; having a pediatrician who conducted a screening specific to autism; the reaction of the pediatrician if parent raised concerns regarding development -

performed more in depth screening, referred child to a specialist, encourage a

"wait and see" approach (other reaction of pediatrician as reference category);

being covered by health insurance, annual household income; and parents' level

of education low and high (middle level as reference category) as independent

variables. Preliminary analyses were conducted to check for violations of

assumptions of normality, linearity, multicollinearity, singularity, and

homoscedasticity and suppression effects. Because of extreme skewness in age

of diagnosis, the logarithm of age of diagnosis was used in this analysis.   The

independent variables of having an older sibling and having a typically

developing older sibling were found to correlate substantially (.779), so the

variable of having an older sibling was removed from the equation. One residual

outlier was eliminated using the SPSS casewise diagnostics routine.

Means, SDs, and intercorrelations for the log base 10 of age of diagnosis

and the predictors are summarized on Table 4. Regression results are

summarized on Table 5. Multiple R for regression was statistically significant,

$F(25, 620)=7.549$, $p<.001$, $R^2=.233$. Six of the 25 independent variables

contributed significantly to the prediction of the logarithm of age of diagnosis.

Having autistic older sibling/s, being referred to ECI, and having a pediatrician

who performed an in-depth screening (in response to parent concerns) were

negatively related to age of diagnosis.   Having first symptoms of non-autism

specific behavioral difficulties, being given a non-ASD diagnosis prior to ASD

diagnosis, and switching pediatricians during first five years of life, were

positively related to age of diagnosis. The remaining 19 variables did not make a

statistically significant contribution (p>.05) to the prediction of the logarithm of age of diagnosis.

The intercorrelations between predictors ranged from .000 to -.633. Being referred to ECI was significantly correlated with the log base 10 of age of diagnosis (-.392). There were significant negative correlations found between having first symptoms of speech and language delays and first symptoms of autistic specific behavioral difficulties (-.415); between being referred to specialist by the pediatrician in response to parent concerns and the pediatrician taking a "wait and see" approach in response to parent concerns (-.633); and low level of parent education and annual household income (-.344). High level of parent education was significantly positively correlated with annual household income (.436).

Table 4.

Means, SD, and Intercorrelations for age of diagnosis of ASD and Predictor Variables

Variable	M	SD	1	2
Age of diagnosis (log base-10)	1.542	.1652	.009	-.031
Predictor Variable				
1.Ethnicity-African American	.02	.156	--	-.015
2.Ethnicity-Asian/Pacific Islander	.01	.096	-.015	--
3.Ethnicity-Hispanic	.05	.220	-.037	-.022
4.Ethnicity-Native American	.00	.056	-.009	-.005
5.Having typically developing older sibling/s	.47	.500	.028	-.027
6.Having developmentally delayed older sibling/s	.11	.313	.008	-.034
7.Having autistic older sibling/s	.08	.277	.024	.029
8.First symptoms-speech and language delays	.54	.499	.009	-.072
9.First symptoms-medical problems	.04	.204	-.034	.059
10.First symptoms-lack of social interest	.11	.317	.006	.016
11.First symptoms-non-autism specific behavioral difficulties	.05	.220	.008	.051
12.First symptoms-autistic-type behaviors	.13	.337	-.032	.011
13.First symptoms-lack of ability to live independently or happily	.00	.068	-.011	-.007
14.Being given a non-ASD diagnosis prior to ASD diagnosis	.64	.479	-.027	.005
15.Being referred to ECI	.85	.361	.012	-.004
16.Switching pediatricians during first five years of life	.57	.496	.058	-.046
17.Having a pediatrician who conducted developmental screenings	.78	.414	.012	-.027
18.Having a pediatrician who conducted autism specific screenings	.25	.435	.045	-.056
19.Reaction of pediatrician to parent concerns-performed in-depth screen	.04	.200	.166	-.020
20.Reaction of pediatrician to parent concerns-referred to specialist	.29	.452	-.035	.010
21.Reaction of pediatrician-encouraged a "wait and see" approach	.50	.500	.000	.032
22.Being covered by medical insurance	.9427	.2326	.039	.024
23.Annual household income	3.40	1.263	-.003	.072
24.Low level of parent education	.14	.347	.022	-.039
25.High level of parent education	.32	.465	-.023	.073

Any correlation greater than .337 is significant at p<.05.

Variable	3	4	5	6
Age of diagnosis (log base-10)	.101	.048	-.025	.057
Predictor Variable				
1.Ethnicity-African American	-.037	-.009	.028	.008
2.Ethnicity-Asian/Pacific Islander	-.022	-.005	-.027	-.034
3.Ethnicity-Hispanic	--	-.013	-.051	.053
4.Ethnicity-Native American	-.013	--	.003	-.020
5.Having typically developing older sibling/s	-.051	.003	--	.093
6.Having developmentally delayed older sibling/s	.053	-.020	.093	--
7.Having autistic older sibling/s	.006	-.017	-.051	.198
8.First symptoms-speech and language delays	.019	-.060	.007	-.060
9.First symptoms-medical problems	-.049	.125	-.004	.071
10.First symptoms-lack of social interest	.095	-.020	-.006	.078
11.First symptoms-non-autism specific behavioral difficulties	.010	-.013	.019	-.014
12.First symptoms-autistic-type behaviors	-.027	.061	-.026	-.048
13.First symptoms-lack of ability to live independently or happily	.088	-.004	.026	-.024
14.Being given a non-ASD diagnosis prior to ASD diagnosis	-.033	.041	-.013	-.038
15.Being referred to ECI	-.077	.024	.008	-.057
16.Switching pediatricians during first five years of life	-.026	-.008	-.002	.006
17.Having a pediatrician who conducted developmental screenings	.021	-.038	-.006	-.088
18.Having a pediatrician who conducted autism specific screenings	.027	-.032	-.023	-.067
19.Reaction of pediatrician to parent concerns-performed in-depth screen	-.013	-.012	.081	-.073
20.Reaction of pediatrician to parent concerns-referred to specialist	.040	-.035	.003	.007
21.Reaction of pediatrician-encouraged a "wait and see" approach	-.007	.056	-.031	-.025
22.Being covered by medical insurance	-.034	.014	-.033	-.062
23.Annual household income	.010	-.084	.038	-.021
24.Low level of parent education	.028	-.022	.111	.059
25.High level of parent education	-.067	-.038	-.091	-.047

Any value greater than .337 is significant at p<.05.

Variable	7	8	9	10
Age of diagnosis (log base-10)	-.047	-.023	-.083	.071
Predictor Variable				
1.Ethnicity-African American	.024	.009	-.034	.006
2.Ethnicity-Asian/Pacific Islander	.029	-.072	.059	.016
3.Ethnicity-Hispanic	.006	.019	-.049	.095
4.Ethnicity-Native American	-.017	-.060	.125	-.020
5.Having typically developing older sibling/s	-.051	.007	-.004	-.006
6.Having developmentally delayed older sibling/s	.198	-.060	.071	.078
7.Having autistic older sibling/s	--	-.078	.018	.016
8.First symptoms-speech and language delays	-.078	--	-.229	-.383
9.First symptoms-medical problems	.018	-.229	--	-.076
10.First symptoms-lack of social interest	.016	-.383	-.076	--
11.First symptoms-non-autism specific behavioral difficulties	-.019	-.249	-.049	-.083
12.First symptoms-autistic-type behaviors	.149	-.415	-.082	-.138
13.First symptoms-lack of ability to live independently or happily	-.021	-.073	-.015	-.024
14.Being given a non-ASD diagnosis prior to ASD diagnosis	-.032	.137	.079	-.092
15.Being referred to ECI	-.058	.086	.048	-.079
16.Switching pediatricians during first five years of life	-.076	.018	-.091	-.006
17.Having a pediatrician who conducted developmental screenings	-.029	.045	-.016	-.035
18.Having a pediatrician who conducted autism specific screenings	-.034	.098	-.054	-.038
19.Reaction of pediatrician to parent concerns-performed in-depth screen	-.007	-.007	-.006	.072
20.Reaction of pediatrician to parent concerns-referred to specialist	.019	.020	-.034	-.075
21.Reaction of pediatrician-encouraged a "wait and see" approach	-.034	.025	-.015	.034
22.Being covered by medical insurance	.002	.024	.052	.046
23.Annual household income	-.056	.109	-.025	-.013
24.Low level of parent education	.040	-.020	.002	-.002
25.High level of parent education	-.073	.092	.035	.010

Any value greater than .337 is significant at $p < .05$.

Variable	11	12	13	14
Age of diagnosis (log base-10)	.127	-.004	-.010	.112
Predictor Variable				
1.Ethnicity-African American	.008	-.032	-.011	-.027
2.Ethnicity-Asian/Pacific Islander	.051	.011	-.007	.005
3.Ethnicity-Hispanic	.010	-.027	.088	-.033
4.Ethnicity-Native American	-.013	.061	-.004	.041
5.Having typically developing older sibling/s	.019	-.026	.026	-.013
6.Having developmentally delayed older sibling/s	-.014	-.048	-.024	-.038
7.Having autistic older sibling/s	-.019	.149	-.021	-.032
8.First symptoms-speech and language delays	-.249	-.415	-.073	.137
9.First symptoms-medical problems	-.049	-.082	-.015	.079
10.First symptoms-lack of social interest	-.083	-.138	-.024	-.092
11.First symptoms-non-autism specific behavioral difficulties	--	-.090	-.016	.055
12.First symptoms-autistic-type behaviors	-.090	--	-.026	-.145
13.First symptoms-lack of ability to live independently or happily	-.016	-.026	--	.051
14.Being given a non-ASD diagnosis prior to ASD diagnosis	.055	-.145	.051	--
15.Being referred to ECI	-.096	-.040	.029	.061
16.Switching pediatricians during first five years of life	.017	.011	.013	.046
17.Having a pediatrician who conducted developmental screenings	.072	-.062	-.019	.058
18.Having a pediatrician who conducted autism specific screenings	-.005	-.023	.013	.045
19.Reaction of pediatrician to parent concerns-performed in-depth screen	-.013	-.058	-.014	.026
20.Reaction of pediatrician to parent concerns-referred to specialist	-.023	.071	.057	.006
21.Reaction of pediatrician-encouraged a "wait and see" approach	.007	-.046	-.023	.032
22.Being covered by medical insurance	-.003	-.063	-.081	-.016
23.Annual household income	-.035	-.094	-.004	.042
24.Low level of parent education	.028	.044	-.027	-.074
25.High level of parent education	-.052	-.104	.003	.081

Any value greater than .337 is significant at p<.05.

Variable	15	16	17	18
Age of diagnosis (log base-10)	-.392	.125	-.041	-.068
Predictor Variable				
1.Ethnicity-African American	.012	.058	.012	.045
2.Ethnicity-Asian/Pacific Islander	-.004	-.046	-.027	-.056
3.Ethnicity-Hispanic	-.077	-.026	.021	.027
4.Ethnicity-Native American	.024	-.008	-.038	-.032
5.Having typically developing older sibling/s	.008	-.002	-.006	-.023
6.Having developmentally delayed older sibling/s	-.057	.006	-.088	-.067
7.Having autistic older sibling/s	-.058	-.076	-.029	-.034
8.First symptoms-speech and language delays	.086	.018	.045	.098
9.First symptoms-medical problems	.048	-.091	-.016	-.054
10.First symptoms-lack of social interest	-.079	-.006	-.035	-.038
11.First symptoms-non-autism specific behavioral difficulties	-.096	.017	.072	-.005
12.First symptoms-autistic-type behaviors	-.040	.011	-.062	-.023
13.First symptoms-lack of ability to live independently or happily	.029	.013	-.019	.013
14.Being given a non-ASD diagnosis prior to ASD diagnosis	.061	.046	.058	.045
15.Being referred to ECI	--	.003	.044	.039
16.Switching pediatricians during first five years of life	.003	--	-.197	-.107
17.Having a pediatrician who conducted developmental screenings	.044	-.197	--	.291
18.Having a pediatrician who conducted autism specific screenings	.039	-.107	.291	--
19.Reaction of pediatrician to parent concerns-performed in-depth screen	-.061	-.068	.092	.217
20.Reaction of pediatrician to parent concerns-referred to specialist	.051	-.231	.138	.239
21.Reaction of pediatrician-encouraged a "wait and see" approach	-.004	.225	-.105	-.260
22.Being covered by medical insurance	.006	-.080	.030	-.056
23.Annual household income	.064	-.026	.068	.002
24.Low level of parent education	-.102	-.020	-.110	.034
25.High level of parent education	.039	-.008	.152	.065

Any value greater than .337 is significant at $p<.05$.

Variable	19	20	21	22
Age of diagnosis (log base-10)	-.059	-.069	.059	-.052
Predictor Variable				
1.Ethnicity-African American	.166	-.035	.000	.039
2.Ethnicity-Asian/Pacific Islander	-.020	.010	.032	.024
3.Ethnicity-Hispanic	-.013	.040	-.007	-.034
4.Ethnicity-Native American	-.012	-.035	.056	.014
5.Having typically developing older sibling/s	.081	.003	-.031	-.033
6.Having developmentally delayed older sibling/s	-.073	.007	-.025	-.062
7.Having autistic older sibling/s	-.007	.019	-.034	.002
8.First symptoms-speech and language delays	-.007	.020	.025	.024
9.First symptoms-medical problems	-.006	-.034	-.015	.052
10.First symptoms-lack of social interest	.072	-.075	.034	.046
11.First symptoms-non-autism specific behavioral difficulties	-.013	-.023	.007	-.003
12.First symptoms-autistic-type behaviors	-.058	.071	-.046	-.063
13.First symptoms-lack of ability to live independently or happily	-.014	.057	-.023	-.081
14.Being given a non-ASD diagnosis prior to ASD diagnosis	.026	.006	.032	-.016
15.Being referred to ECI	-.061	.051	-.004	.006
16.Switching pediatricians during first five years of life	-.068	-.231	.225	-.080
17.Having a pediatrician who conducted developmental screenings	.092	.138	-.105	.030
18.Having a pediatrician who conducted autism specific screenings	.217	.239	-.260	-.056
19.Reaction of pediatrician to parent concerns-performed in-depth screen	--	-.132	-.209	.018
20.Reaction of pediatrician to parent concerns-referred to specialist	-.132	--	-.633	-.021
21.Reaction of pediatrician-encouraged a "wait and see" approach	-.209	-.633	--	.020
22.Being covered by medical insurance	.018	-.021	.020	--
23.Annual household income	-.011	.035	-.023	.105
24.Low level of parent education	-.039	.012	.027	-.170
25.High level of parent education	-.025	.019	-.020	.053

Any value greater than .337 is significant at p<.05.

Variable	23	24	25
Age of diagnosis (log base-10)	-.089	.083	-.084
Predictor Variable			
1.Ethnicity-African American	-.003	.022	-.023
2.Ethnicity-Asian/Pacific Islander	.072	-.039	.073
3.Ethnicity-Hispanic	.010	.028	-.067
4.Ethnicity-Native American	-.084	-.022	-.038
5.Having typically developing older sibling/s	.038	.111	-.091
6.Having developmentally delayed older sibling/s	-.021	.059	-.047
7.Having autistic older sibling/s	-.056	.040	-.073
8.First symptoms-speech and language delays	.109	-.020	.092
9.First symptoms-medical problems	-.025	.002	.035
10.First symptoms-lack of social interest	-.013	-.002	.010
11.First symptoms-non-autism specific behavioral difficulties	-.035	.028	-.052
12.First symptoms-autistic-type behaviors	-.094	.044	-.104
13.First symptoms-lack of ability to live independently or happily	-.004	-.027	.003
14.Being given a non-ASD diagnosis prior to ASD diagnosis	.042	-.074	.081
15.Being referred to ECI	.064	-.102	.039
16.Switching pediatricians during first five years of life	-.026	-.020	-.008
17.Having a pediatrician who conducted developmental screenings	.068	-.110	.152
18.Having a pediatrician who conducted autism specific screenings	.002	.034	.065
19.Reaction of pediatrician to parent concerns-performed in-depth screen	-.011	-.039	-.025
20.Reaction of pediatrician to parent concerns-referred to specialist	.035	.012	.019
21.Reaction of pediatrician-encouraged a "wait and see" approach	-.023	.027	-.020
22.Being covered by medical insurance	.105	-.170	.053
23.Annual household income	--	-.344	.436
24.Low level of parent education	-.344	--	-.273
25.High level of parent education	.436	-.273	--

Any value greater than .337 is significant at $p < .05$.

Table 5.

Multiple Linear Regression analysis summary for the prediction of age of diagnosis of ASD

Predictor Variable	B	SE	β
Ethnicity-African American	.030	.038	.028
Ethnicity-Asian/Pacific Islander	-.030	.061	-.018
Ethnicity-Hispanic	.046	.027	.061
Ethnicity-Native American	.172	.107	.058
Having typically developing older sibling/s	-.010	.012	-.030
Having developmentally delayed older sibling/s	.023	.020	.044
Having autistic older sibling/s	-.045	.022	-.075*
First symptoms-speech and language delays	.022	.019	.068
First symptoms-medical problems	-.035	.033	-.043
First symptoms-lack of social interest	.047	.024	.090
First symptoms-non-autism specific behavioral difficulties	.074	.031	.099*
First symptoms-autistic-type behaviors	.022	.024	.044
First symptoms-lack of ability to live independently or happily	-.006	.088	-.003
Being given a non-ASD diagnosis prior to ASD diagnosis	.050	.013	.145***
Being referred to ECI	-.174	.017	-.380***
Switching pediatricians during first five years of life	.031	.013	.093*
Having a pediatrician who conducted developmental screenings	.007	.015	.018
Having a pediatrician who conducted autism specific screenings	-.014	.015	-.038
Reaction of pediatrician-performed in-depth screen	-.073	.034	-.089*
Reaction of pediatrician-referred to specialist	-.019	.018	-.053
Reaction of pediatrician-encouraged a "wait and see" approach	-.013	.016	-.039
Being covered by medical insurance	-.021	.026	-.029
Annual household income	-.004	.005	-.030
Low level of parent education	.013	.019	.027
High level of parent education	-.019	.014	-.054

Note: R-square = .234 (N = 646, p < .000).

* p < .05; ** p < .01; *** p < .001.

Chapter V

Discussion

The purpose of this study was to examine age of diagnosis and factors related to age of diagnosis of autistic disorder and PDD-NOS in the United States. Results of this study indicate that average age of diagnosis is 37.78 months or about 3 years 2 months of age. The findings are consistent with Filipek et al. (1999) who reported that average age of diagnosis in the United States is between 3 and 4 years. However, age of diagnosis in this sample varied considerably, ranging from 14 months of age to 119 months of age.

Results indicate that there are geographic trends in age of diagnosis of children with autistic disorder and PDD-NOS in the United States. For the purpose of statistical analyses the log-base 10 transformation for age of diagnosis was used to determine the presence of statically significant differences in age of diagnosis among the four regions of the United States. For ease of interpretation, average ages of diagnoses prior to logarithm transformation are: Northeast 35.3 months; Midwest, 42.1 months; South 35.5 months; West 39.2 months. Average age of diagnosis in the Northeast and South were similar and significantly earlier than average age of diagnosis in the Midwest Region.

A significant negative correlation was found between date of birth and age at diagnosis. In other words, the older children in the sample were more likely to be diagnosed later and the younger children had a tendency to be diagnosed at earlier ages. This finding indicates that, in general, children are being diagnosed at younger ages and is consistent with Rutter's (2006) report.

The study also examined which specific sociodemographic factors, clinical factors, and pediatrician practices predicted age of diagnosis of ASD. In this case, about 23% of the variance in age of diagnosis is explained by the regression model. Having autistic older sibling/s, having first symptoms of non-autism specific behavioral difficulties, being given a non-ASD diagnosis prior to ASD diagnosis, being referred to ECI, switching pediatricians during first five years of life, and having a pediatrician who performed an in-depth screening (in response to parent concerns) contributed significantly to the regression model. Having first symptoms of lack of social interest approached significance (p=.057). The remaining variables did not approach significance or significantly predict age of diagnosis.

Being referred to ECI had the greatest unique contribution to the prediction of age of diagnosis. Being referred to ECI was negatively correlated with the logarithm for age of diagnosis, indicating that being referred to ECI was associated with earlier age of diagnosis. Although ECI does not typically provide diagnostic services, referral to ECI when concerns are noted is consistent with practice parameters proposed by Filipek et al. (1999).

Having autistic older sibling/s was also negatively correlated with the logarithm for age of diagnosis. This finding is not surprising, as once a family history of ASD is established caretakers are likely to be more vigilant for early signs of autism and more proactive in assuring an earlier diagnosis. Pediatricians are also charged with being extra attentive to signs of autism in siblings of children diagnosed with ASD (American Academy of Pediatrics, 2001).

In addition, the recent explosion in sibling studies, (Bryson et al., 2007; Loh et al., 2007; Mitchell et al., 2006; Zwaigenbaum et al., 2007) have shed light on the fact that younger siblings of effected children are at higher risk for developing ASD.

As anticipated, having a pediatrician who performed an in-depth screening in response to parent concerns predicted an earlier age of diagnosis. This practice is consistent with practice parameters set forth by the American Academy of Pediatrics (American Academy of Pediatrics, 2001; Johnson & Myers, 2007).

Switching pediatricians during the first five years of life was positively correlated with age of diagnosis. This finding was expected given Mandell's (2005) findings. When a child switches pediatricians, the ongoing developmental surveillance proposed by Johnson and Myers (2007) is likely disrupted, which can, in turn, delay diagnosis.

Having first symptoms of non-autism specific behavioral difficulties and being given a non-ASD diagnosis prior to ASD diagnosis, were also associated with later diagnosis. These findings are consistent with results reported by Mandell et al. (2007) who found that children with ASD who were first diagnosed with another disorder were most commonly diagnosed with disruptive behavior disorders including ADHD and conduct disorder, which resulted in delayed ASD diagnosis.

Although the results of this study do not support a relationship between the child's ethnicity, whether the child was referred to a specialist in response to parent concerns, whether the child was covered by health insurance, annual

household income, and parents' level of education and age of diagnosis of ASD, other studies (Filipek, 1999; Goin-Kochel et al., 2006; Mandell et al., 2002; Mandell et al., 2005; Mandell et al. 2007) do support a relationship between these variables and age of diagnosis. However, compared to the previous studies, this study used far more predictors which may be competing with each other. It is also possible that the non-significant findings in this study are a function of the obtained sample and require further review.

One question raised during the dissertation defense was whether age of diagnosis differs by gender. An independent samples t-test was conducted to address this question. There was no significant difference in log base 10 age of diagnosis scores for males (M=.1656, SD=.0070) and females (M=.1668, SD=.0167); t (653) = -.187, p=.85 (two-tailed).

Implications

Results of this study indicate that average age of diagnosis in the United States is within the range reported by Filipek et al. in 1999. Over the past few years there has been a concerted effort to increase public awareness of autism and its symptoms. The "autism epidemic" has been the topic of many newspaper and magazine articles and television programs. One of the obvious goals of increasing public awareness is earlier detection of symptoms, which should result in earlier diagnosis, which should result in earlier treatment. Although the results of this study demonstrate that average age of diagnosis is still within the range reported by Filipek almost ten years ago, the results are also promising, as younger children in the study were likely to be diagnosed at younger ages. It

should be noted that this study included children up to ten years of age, and, therefore, a subset of the sample, who contributed to the mean age or diagnosis, were likely diagnosed prior to the efforts on increasing public awareness.

Results of this survey indicate that about 78% of the participant's pediatricians screened for general developmental problems, while only about 25% conducted screenings specific to autism. In addition, when parents raised concerns regarding their child's development, the most common reaction by pediatricians was to take a "wait and see approach" (50%). These ancillary results are of particular importance in light of the report by the American Academy of Pediatrics (Johnson & Myers, 2007).   This policy report charges all pediatricians to engage in both ongoing surveillance of young children and autism specific screenings at 18-months and 24-months of age.

Limitations

This study is subject to several limitations. Participation in the study was limited to individuals with internet access. This may have excluded potential participants from lower income groups, who are less likely to have internet access. All income levels were represented in the study, but the greatest percent of participants were in the highest income bracket (26%) and the fewest number of participants came from the lowest income bracket (7%).   Individuals in the lowest income bracket may also be less likely to visit the doctor, may be less likely to notice early symptoms of ASD, and may be less likely to receive an early diagnosis. Minorities were also grossly underrepresented in the study, as 89% of the participants were Caucasian. Children who are not members of the dominant

culture are more likely to have substandard primary care, which may affect referral to a specialist for a diagnosis. The study was also limited to individuals who read and understand English well enough to participate in the study. In particular, this limitation may have excluded Hispanic individuals, who make up an increasing percentage of the U.S. population. Parents who are members of IAN or likely to participate in an IAN sponsored research study may represent a specific subset of the population which is not representative of the mainstream population in the United States. In this study about 85% of fathers and 89% of mothers had at least some college or vocational training. It follows that parents who are members of IAN may be more educated and more attuned to their child's development than that of typical parents, which may have further biased the sample. Therefore, it is probable that the average age of diagnosis reported in this study is lower than that of the general population. It is also possible that given a sample more diverse in ethnicity and socioeconomic status, average age of diagnosis would not have shown a decrease. In particular, it is likely that average age of diagnosis has not changed among the poor, who have restricted access to medical doctors.

Several of the variables in the study including; age of child when diagnosed, age when parents first noticed symptoms, whether the pediatrician conducted developmental screenings or screenings specific to autism, use retrospective data. Although some participants may be very accurate in their reporting, other reports may differ significantly from reality, limiting the validity of the data. The questions with the most missing data were whether the

pediatrician conducted developmental assessments and whether the pediatrician conducted autism specific assessments. This is likely due to the fact that this is information which parents may not remember soon after the doctor appointments, and so, a greater number of participants skipped these questions. Research on obtaining reliable past medical history has concluded that people are better at remembering when specific events occurred compared to thoughts and actions (Redelmeier, Tu, Schull, Ferris, & Hux, 2001). This would indicate that parents are likely more accurate in reporting the when their child was diagnosed as it is a specific event than they would be at reporting age when they first noticed symptoms or whether their child's physician conducted screenings. According to Redelmeier et al. (2001), people's subjective evaluations are influenced by extraneous factors and people often focus on coincidences and neglect contrary data. It is, therefore, possible that parents who were unhappy with their child's diagnostic process were more likely to report that their pediatrician did not conduct screenings when the screenings were administered or that their pediatrician encouraged a wait and see approach when this was not the case. It is also possible that parents remembered first noticing symptoms following a specific event, such as 18-month immunizations, because this has been a hypothesized explanation for the "autism epidemic."

The generalizability of the results is limited. First, the study was only disseminated to members of IAN who agreed to participate in autism research and who met inclusion criteria. Some study participants may have been made aware of the study through the link posted on the IAN Community Research

Opportunities Bulletin Board. Nevertheless results of the study may not be generalizable to those who are unaware of or unaffiliated with IAN. Second, only about 21% of the individuals who received a study recruitment letter actually participated in the research. IAN participants are frequently solicited to participate in research and so those who actually respond to the solicitations may represent a certain subset of the population of parents who have children with autism and may not be representative parents of children with autism in general and parents who have registered with IAN.   Third, this analysis made use of a correlational/cross-sectional design so, causal inferences cannot be made and findings can not be generalized to other time points.

Future Research

Several suggestions for future research may be offered. A sample more diverse in terms of ethnicity and socio-economic factors should be used to further explore which factors predict early identification of ASD. A sample, which is comprised of a more balanced number of participants per state, should by employed to determine whether age of diagnosis differs significantly by state.   In addition, data collection techniques should include methods beyond surveying, such as a review of records that includes child's level of functioning across domains. Wiggins, Baio, and Rice (2006) found that level of impairment predicted age of diagnosis, with children with severe impairment being diagnosed about 17 months earlier than children with mild impairment. Despite this finding, level of impairment was not included in this study as it is highly subjective and difficult to quantify for survey research. It is, therefore, crucial that future studies

in this area include methods of data collection that are compatible with the inclusion of a severity factor as a predictor of age of diagnosis. Future studies should also consider including regression, using a standardized measure such as the ADI-R regression criteria, as a predictor of age of diagnosis.

Practice Implications

Perhaps there are lessons to be learned from a two year implementation of practice parameters conducted in Switzerland. The goal of this study was to decrease average of age of diagnosis. Results of the study indicated that during the implementation period mean age of diagnosis was reduced by 1.5 years; however, the reduction in age of diagnosis was not maintained following the conclusion of the study. The authors suggest that perhaps the best way to enforce practice parameters is to implement a systematic screening program (Holzer, Mihailescu, Rodrigues-Degaeff, Junier, Muller-Nix, and Halfon, et al. 2006).

Robins (2008) suggests that the M-CHAT screener can be easily and routinely administered in a healthcare provider's office. Information from the M-CHAT can then be incorporated with information from the general screening to maximize early detection of ASD. A follow-up interview by the physician or paraprofessional can further determine risk for an ASD and need for referral for an autism assessment. Branson, Vigil, and Bingham (2008) suggest that since research has shown that the majority of pediatricians have difficulty following practice parameters, other community professionals who regularly interact with young children be targeted to assist with the early identification process. They

believe that community childcare settings are the ideal locations for ongoing

monitoring, screening, and referral of children at-risk for ASD. Recommendations

resulting from a recent study conducted in Jamaica on the role of early childhood

professionals in the early identification of ASD calls for general education on the

key features of autism, as well as targeted education for first-contact health and

education professionals.   The authors of the study also suggest educating these

professionals on the use of autism screening tools (Samms-Vaughn & Franklyn-

Banton, 2008).

The age at which it is possible to reliably diagnose autism remains a hotly

debated issue. Holzer, et al. (2006), suggest using the classification of "autistic

risk." This classification would allow for early intervention without prematurely

shutting a child into a state if ASD.   The position of Brian, et al. (2008) is

consistent with the suggestion of Holzer, et al. Brian, et al. suggest that in the

presence of diagnostic uncertainty, clinicians should help families move forward

in making intervention decisions, acknowledging that reevaluation may

necessary.   Regardless of whether a firm diagnosis can be made, interventions

should be initiated as soon as concerns are raised.

Conclusion

This study indicates that although average age of diagnosis in the U.S.

appears to be decreasing, more work in the area of early identification of ASD is

needed. Results of this study suggest that more targeted efforts need to take

place in the Midwest, where age of diagnosis was found to be significantly later

than in the Northeast and South regions. This study also identifies some factors

associated with age identification of ASD, which may useful when developing

programs for early identification of ASD.   Results of recent studies suggest that

if we are to systematically reduce age of diagnosis, implementation of a

methodical screening program which uses either early childhood educators

and/or medical personnel is needed.   The author agrees that consideration

should be given to use of the classification of "autistic risk" so that intervention is

not delayed as a child awaits a definitive diagnosis. This, of course, would

require cooperation from third-party payers.

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Appendix A

Dear IAN Research participant,

Based on your family profile, one or more members of your family may qualify for the study, below. You should contact the researcher directly, using the information provided, if you are interested in joining.

You do not have to participate in this study and your non-participation will neither affect the care you receive from any health provider nor your standing as a participant in IAN Research.

Please note that IAN Research is serving as a resource linking the autism community and researchers. This study is not endorsed by or performed under the auspices of the IAN Research project at Kennedy Krieger Institute/Johns Hopkins.

Name of Study: Predictors of Early Identification of Children with Autism Spectrum Disorders
Eligibility Criteria: Children aged ten years or younger who have been diagnosed with Autistic Disorder or PDD-NOS
Principal Investigator: Chana R. Adelman, M.A., Doctoral Candidate, University of Houston
Contact Information: email: chanaadelman@yahoo.com, phone: (713) 882-1200
Faculty Sponsor: Dr. Tom Kubiszyn,University of Houston
Contact Information: email: tkubiszyn@uh.edu, phone: (713) 743-9865

Dear Parent,

I am writing to offer your child(ren) an opportunity to participate in an online research study. This project has been reviewed by the University of Houston Committee for the Protection of Human Subjects (713) 743-9205. The study is looking primarily at predictors of early identification of children with Autistic Disorder or PDD-NOS. If applicable, the survey may be completed for each of your eligible children.

The survey takes approximately ten minutes to complete. If you are interested in participating, please click on the link below, which will take you directly to the survey.
https://www.surveymonkey.com/s.aspx?sm=vDtG3edXz0cH5IRkcpbIKw_3d_3d

Thank you in advance for your time and assistance.

Sincerely,

Chana R. Adelman, M.A.
Doctoral Candidate
Department of Educational Psychology
University of Houston

Appendix B

Exploring Practices of Diagnosing Autism-Revised

Consent

UNIVERSITY OF HOUSTON
CONSENT TO PARTICIPATE IN RESEARCH

PROJECT TITLE: Predictors of Early Identification of Children with Autism Spectrum Disorders

You are being invited to participate in a research project conducted by Chana Adelman from the Department of Educational Psychology at the University of Houston. This project will collect data for the researcher's dissertation project, which is under the supervision of Dr. Tom Kubiszyn. To be eligible to participate, you must be a parent of a child who is ten years old or younger and has been diagnosed with autism or pervasive developmental disorder.

NON-PARTICIPATION STATEMENT
Your participation is voluntary and you may refuse to participate or withdraw at any time without penalty or loss of benefits to which you are otherwise entitled. You may also refuse to answer any question.

PURPOSE OF THE STUDY
Early identification of Autism Spectrum Disorders leads to early intervention, which can result in improved outcomes. This nationwide study will explore age of diagnosis and age when problems were first identified. The study will also explore factors that predict age of diagnosis.

PROCEDURES
You will be one of approximately 1,000 subjects to be asked to participate in this project. You will be administered a survey which will take under 10 minutes to complete. Your name will not be recorded on survey materials and participation in the study will remain anonymous. The data gathered online will not be linked to you in any way.

CONFIDENTIALITY
Your participation in this project is anonymous.

RISKS/DISCOMFORTS
Although unlikely, it is possible that, because the survey draws attention to diagnostic practices, the completion of the survey measure may create some discomfort for people who experienced dissatisfaction with the diagnostic process and/or services offered to their child.

BENEFITS
While you will not directly benefit from participation, your participation may help investigators better understand factors that affect early identification of autism spectrum disorders.

ALTERNATIVES
Participation in this project is voluntary and the only alternative to this project is non-participation.

PUBLICATION STATEMENT
The results of this study may be published in professional and/or scientific journals. The results may also be used for educational purposes or for professional presentations. However, no individual subject will be identified.

If you have any questions, you may contact Chana Adelman at 713-882-1200. You may also contact Dr. Tom Kubiszyn, faculty sponsor, at 713-743-9865.

ANY QUESTIONS REGARDING YOUR RIGHTS AS A RESEARCH SUBJECT MAY BE ADDRESSED TO THE UNIVERSITY OF HOUSTON COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS (713-743-9204). ALL RESEARCH PROJECTS THAT ARE CARRIED OUT BY INVESTIGATORS AT THE UNIVERSITY OF HOUSTON ARE GOVERNED BY REQUIREMENTS OF THE UNIVERSITY AND THE FEDERAL GOVERNMENT.

Your acceptance and completion of the research packet constitutes your informed consent of the conditions of the study.

Exploring Practices of Diagnosing Autism-Revised

* Once you have read the above consent information please select one of the options below.

○ Yes - I agree to participate in this research.

○ No - I do not agree to participate in this research.

Exploring Practices of Diagnosing Autism-Revised

Autism Survey

What is your child's date of birth?

| MM | DD | YYYY |
DOB | ___ / ___ / ___ |

What is your child's gender?

○ male

○ female

What is your child's primary ethnicity?

○ African American

○ Asian/Pacific Islander

○ Caucasian

○ Hispanic

○ Native American

○ Other

Does your child have any older siblings?

○ Yes

○ No

If your child does have an older sibling, answer "yes" or "no" to the next three questions. If your child does not have an older sibling answer "not applicable" to the next three questions.

Does your child have one or more older siblings that are typically developing?

○ Yes

○ No

○ Not applicable

Does your child have one or more older siblings that experienced some type of developmental delay other than an autism spectrum disorder?

○ Yes

○ No

○ Not applicable

Exploring Practices of Diagnosing Autism-Revised

Does you child have one or more older siblings that have been diagnosed with an autism spectrum disorder?

○ Yes

○ No

○ Not applicable

In what city and state were you living at the time that your child was first diagnosed with an Autism Spectrum Disorder?

_____

What is your child's current diagnosis?

○ Autism

○ Asperger's Disorder

○ Pervasive Developmental Disorder, NOS

○ Rett's Disorder

○ Child Disintegrative Disorder

○ Unknown, but some category of Autism or PDD

With which of the following was your child diagnosed prior to being diagnosed with an autism spectrum disorder?

☐ Attention Deficit Hyperactivity Disorder

☐ Auditory Processing Disorder

☐ Developmental Delay

☐ Mental Retardation

☐ Sensory Integration Disorder

☐ Speech/Language Delay

☐ None

☐ Other-please comment

_____

At what age was your child diagnosed with the an autism spectrum disorder (in years and months)?

	Years	Months
Age	[____] ▼	[____] ▼

Exploring Practices of Diagnosing Autism-Revised

What were the first symptoms that caused concern?

○ Speech/language delays

○ Medical problems or delays in milestones other than language

○ Lack of interest in social/emotional responses to people (difficulties in playing with other children, being in his/her "own world")

○ Behavioral difficulties not specific to autism (sleeping or eating problems, high activity level, aggression)

○ Autistic-type behaviors (hand or finger mannerisms, unusual attachments, trouble with change, unusual play with objects)

○ Lack of ability to live independently or happily

○ Other-please comment

_____

How old was your child when you or another caretaker first noticed that your child was not developing normally (in years and months)?

	Years	Months
Age	[ ] ▼	[ ] ▼

Who was the first to notice that your child was not developing normally?

○ Parent

○ School/Day Care Personnel

○ Pediatrician

○ Other Health Care Provider

○ Other-please comment

_____

Who initiated the referral for the autism evaluation?

○ Parent

○ School/Day Care Personnel

○ Pediatrician

○ Other Health Care Provider

Other (please comment)

Exploring Practices of Diagnosing Autism-Revised

Who was the first person to diagnose your child with an autism spectrum disorder?

○ School district personnel

○ Pediatrician

○ Psychologist outside the school setting

○ Psychiatrist

○ Neurologist

○ Other-please comment

Was your child referred to ECI (Early Childhood Intervention)?

○ Yes

○ No

Did you switch pediatricians when your child was between the ages of one and five?

○ Yes

○ No

If your child did switch pediatricians between the ages of one and five, answer the next three questions regarding the pediatrician who treated your child for the majority of the time when your child was between one and five years of age.

Did/Does your child's pediatrician ask you or your child questions that appear to be assessing your child's development?

○ Yes

○ No

Did/Does your child's pediatrician ask you or your child questions that appeared to be assessing for autism?

○ Yes

○ No

Prior to your child's diagnosis, did you raise concerns regarding your child's development to your pediatrician?

○ Yes

○ No

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Which of these best describes the reaction of your pediatrician when you raised concerns?

- ○ Performed a more in-depth screening
- ○ Referred your child to a specialist
- ○ Encouraged you to "wait and see" how your child develops
- ○ Not applicable
- ○ None of the above-please comment
  _____

Was your child covered by some type of medical insurance during his/her first five years of life?

- ○ Yes, the entire time
- ○ Yes, part of the time
- ○ No

What is your annual household income?

- ○ Under $25,000
- ○ $25,000-$50,000
- ○ $50,001-$75,000
- ○ $75,001-$100,000
- ○ More than $100,000

What is the highest level of education achieved by your child's parents?

	Some high school	High school diploma/GED	Some college or vocational training	Bachelor's degree	More than a bachelor's degree
Father	○	○	○	○	○
Mother	○	○	○	○	○

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Non-Consent

Your participation is required to participate in this survey. Please select "Yes" if you wish to participate in this survey.

Exploring Practices of Diagnosing Autism-Revised

Thank You

Thank you for your participation in this study. Have a nice day!

Appendix C

Northwest:	#	%	South:	#	%
Connecticut	11	.0168	Alabama	4	.0061
Maine	3	.0046	Arkansas	4	.0061
Massachusetts	24	.0367	Delaware	2	.0031
New Hampshire	1	.0015	District of Columbia	0	0
New Jersey	24	.0367	Florida	28	.0428
New York	49	.0749	Georgia	30	.0459
Pennsylvania	40	.0612	Kentucky	7	.0107
Rhode Island	2	.0031	Louisiana	5	.0077
Vermont	0	0	Maryland	31	.0474
			Mississippi	2	.0031
Midwest:			North Carolina	17	.0260
Illinois	35	.0535	Oklahoma	4	.0061
Indiana	16	..0245	South Carolina	10	.0153
Iowa	2	.0031	Tennessee	12	.0183
Kansas	11	.0168	Texas	41	.0627
Michigan	12	.0183	Virginia	22	.0336
Minnesota	16	.0245	West Virginia	3	.0046
Missouri	28	.0428			
Nebraska	4	.0061	**West:**		
North Dakota	4	.0061	Alaska	3	.0046
Ohio	25	.0382	Arizona	8	.0122
South Dakota	1	.0015	California	50	.0765
Wisconsin	14	.0214	Colorado	5	.0077
			Hawaii	2	.0031
			Idaho	3	.0046
			Montana	2	.0031
			Nevada	6	.0092
			New Mexico	3	.0046
			Oregon	8	.0122
			Utah	7	.0107
			Washington	13	.0199
			Wyoming	0	0

#= The number of participants from the state.
%=The percentage of participants from the state.