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Early Diagnosis and Intervention For Young Children with Autism Spectrum Disorder in New York State

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EARLY DIAGNOSIS AND INTERVENTION FOR YOUNG CHILDREN WITH AUTISM SPECTRUM DISORDER IN NEW YORK STATE

By

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FOR YOUNG CHILDREN WITH AUTISM SPECTRUM DISORDER
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ABSTRACT

This study examined the prevalence of autism spectrum disorder (ASD), analyzed the trends, assessed children's sociodemographic characteristics and examined timing of ASD diagnosis among children who enrolled in the New York State Early Intervention Program (NYSEIP).

Secondary data from the New York State Early Intervention data systems were used. The systems include NYEIS (New York State Early Intervention System), a centralized web-based system that electronically manages the NYSEIP administrative tasks and was designed to support the NYSEIP's services, and the legacy data system: KIDS (Kids Integrated Data System). The time-trend design employed in this study was a form of longitudinal ecological study, and was intended to provide a dynamic view of ASD status in the NYSEIP. Data were collected from the NYSEIP from 2005 to 2014 referral year, to look for trends and changes.

This study found that prevalence of ASD in at-risk children was higher than the estimated prevalence in the general population. ASD diagnoses have been increasing among at-risk children who enrolled in the NYSEIP. The increase was comparable to the national trends. In general, there were upward trends in the prevalence of ASD in all sub-groups over the study period, with a different pattern of prevalence between New York City and the Rest of the State.

In addition, the analysis also indicated that there were some discrepancies in age at ASD diagnosis and time to receive ASD diagnosis by race and geographical location. Children residing in Western and Central Region were diagnosed with ASD at an older age than children from other parts of New York State and had a longer time to receipt of the diagnosis after referral to the NYSEIP. Trend analyses demonstrated that the timing of services for ASD children in NYSEIP remained similar from 2005 to 2014.

The results from this analysis suggest that monitoring ASD trends is important for the effective and efficient planning of programs such as the NYSEIP. In addition, this study can inform local early intervention providers and healthcare professionals about the experience of evaluating children for ASD in the NYSEIP. By design, this study was intended to generate several important hypotheses for future research and contributes useful insights for the NYSEIP.

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"For from Him and through Him and to Him are all things. To Him be the glory forever. Amen." (Romans 11:36)

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LIST OF ABBREVIATIONS

Abbreviation	**Description**
AAP	American Academy of Pediatrics
ABA	Applied Behavior Analysis
ADDM	Autism and Developmental Disabilities Monitoring
ANOVA	Analysis of Variance
ASD	Autism Spectrum Disorder
CDC	Center for Disease Control and Prevention
CFR	Code of Federal Regulations
CI	Confidence Interval
CMS	Center for Medicare and Medicaid Services
DSM-4	Diagnostic and Statistical Manual of Mental Disorders, Fifth Version
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Version
EIBI	Early Intensive Behavioral Intervention
EIOs	Early Intervention Officials
EIP	Early Intervention Program
GIS	Geographic Information System
ICD-9	International Classification of Disease, Ninth Version
ICD-10	International Classification of Disease, Tenth Version
IDEA	Individuals with Disability Education Act
IFSP	Individualized Family Service Plan
KIDS	Kids Integrated Data System (NYSEIP legacy data system)
LSED	Longitudinal Study of Early Development

MCAR	Missing Completely at Random
NCBDDD	National Center of Birth Defects and Developmental Disabilities
NHIS	National Health Interview Study
NSCH	National Survey of Children’s Health
NYC	New York City
NYEIS	New York Early Intervention System (NYSEIP data system)
NYS	New York State
NYSEIP	New York State Early Intervention Providers
NYSDOH	New York State Department of Health
PELL	Pregnancy to Early Life Longitudinal
PHL	Public Health Law
ROS	Rest of State (excludes NYC)
SAS	Statistical software product (SAS Institute Inc. ©)
SD	Standard Deviation

CHAPTER 1.

INTRODUCTION

1.1. Background

Autism spectrum disorder (ASD) is a complex neurodevelopmental disorder characterized by difficulties in social interaction, impairment in communication and repetitive behavior.[1,2] ASD can result in mild to severe difficulties in thinking and learning which can significantly impede an individual's ability to lead a fulfilling life and mature to independence.[3,4] ASD is an urgent public health concern, because of the tremendous increase in the prevalence of ASD in the United States and worldwide and high cost of its lifelong effects.[5–15] Increasing prevalence of ASD is marked by significant variation by age, sex, race/ethnicity, socioeconomic status and geographic area.[16–24]

The etiology of this condition is not known, and no specific medications can treat the core symptoms of ASD. Early identification of ASD and initiation of developmental services at young age have been shown to improve developmental and educational outcomes.[25–31] To ensure early intervention is delivered, ASD must be diagnosed in early life. However, since there is no medical test for ASD, diagnosis can be difficult. Evaluation of child's behavior and development allows professionals to make an ASD diagnosis. ASD can be reliably diagnosed in children as young as 18 months but many children are diagnosed later in life which delays initiation of services and may impact children's prognosis.[41–43]

Routine developmental screening with appropriate diagnosis and treatment for ASD for children through three years of age is available through state-coordinated early intervention services, under Part C of the Individuals with Disabilities Education Act (IDEA).[35] In 1993, New York State established the New York Early Intervention Program (NYSEIP) for infants and toddlers (up to 36 months) with disabilities and their families.[36] State and federal law and regulations require that children who are suspected of having developmental delay such as ASD are referred to their local Early Intervention Program and are entitled to receive a comprehensive, multidisciplinary evaluation to determine whether they meet the eligibility criteria for the Early Intervention Program (EIP).[35,36]

For individuals and families who are affected by this condition, having a timely ASD diagnosis is important to access appropriate treatment as early as possible and to have better quality of life. Early intervention services address a child's unique needs and are intended to support the development of the child. Services in EIP are agreed upon in the Individual Family Service Program (IFSP), which describes child's current levels of functioning and anticipated goals. Services may include, but are not limited to, speech and language instruction, occupational therapy, physical therapy, Applied Behavior Analysis (ABA) and psychological evaluation. For the families, services may include training to help reinforce the child's new skills and counseling to support the family.

This study examined trends and prevalence of early ASD diagnosis by sociodemographic characteristics such as gender, race/ethnicity, insurance status and geographic location in a group of individuals enrolled in the NYSEIP. In addition, this study also looked at age at and time to have ASD diagnosis for young children. Results of this study may provide information for future policy making and allocation of community resources. In addition, information on trends and patterns of ASD diagnosis including timing of ASD diagnosis allows the assessment of morbidity and the disease burden in New York.

1.2. Diagnosis and Treatment of Autism Spectrum Disorder

ASD diagnosis is made through an evaluation by a professional or team by evaluating behavioral characteristics of a child. For the diagnosis, delay is identified in the areas of communication, socialization, or restricted behavior. Typically, children receive a developmental screening during their “well child” check-ups. If concerns are raised, a comprehensive evaluation is provided.

According to American Academic of Pediatrics (AAP), developmental screening is a short test to tell if children might have delays when age-appropriate basic skills are not found. All children should be screened for developmental delays and disabilities during regular well-child doctor visits at: 9 months, 18 months and 24 or 30 months. In addition, screening for ASD should be conducted during regular well-child doctor visits at: 18 months and 24 months. If concerns identified during the screening, a comprehensive diagnostic evaluation is administered. Comprehensive evaluation is a thorough review that may be conducted by a primary care doctor or a specialist. This evaluation may include a hearing and vision screening, genetic testing, neurological testing, and other medical testings.[37]

Intervention for ASD includes different types of treatments that can generally be broken down into behavior and communication approaches, dietary approaches and medication.[38] An evidence-based intervention for ASD is called applied behavior analysis (ABA) which has become widely accepted among health care professionals and used in many schools and treatment clinics.[39–41] ASD diagnosis is not required for early intervention treatment services. Research reveals that early intervention for children with ASD significantly improves brain structure and function which is the key for optimizing outcomes for children with the disorder, particularly for cognitive improvement, social interaction enhancement and communication development.[27,42–46,41] In addition, early intervention is also needed for improving the quality of affected family's or caretakers' life and society.[47–50]

1.3. Epidemiology of Autism Spectrum Disorder

About 1 in 68 or 1.5% of children were identified with ASD across the United States in 2012. The report from the Centers for Disease Control and Prevention (CDC) announced about a 122 % increase of ASD prevalence occurred since 2002. Studies have revealed that along with the increasing numbers of individuals with ASD, some discrepancies were also found for its diagnosis and intervention, in terms of age of diagnosis,[17,18,51,52] gender,[20,53]race/ ethnicity,[54,55]socioeconomic status[22,56] and geographic distribution.[23,24]The rapid increase of ASD prevalence requires continued monitoring on the trends in the population. In addition, monitoring the prevalence of ASD can assist planning and allocation of resources.

Increases in ASD prevalence have been reported from several studies using different methodologies and sample populations. The CDC's largest ongoing ASD tracking system in the United States: the Autism and Developmental Disabilities Monitoring (ADDM) Network provides updated population-based estimates of the prevalence of ASD in their 11-study site. The initial surveillance year by the ADDM network in 2000 reported that ASD affected one in 150 children (6.7 per 1,000 children) and jumped to one in 68 children (14.6 per 1,000 children) in 2012.[5] Another prevalence study which was based on parental report (National Health Interview Survey) indicated a 289% increase in Autism (from 0.19% in 1997-1998 to 0.74% in 2006-

2008). Similarly, a population-based developmental disabilities surveillance program for 8-year-olds in metropolitan Atlanta reported a 269% increase in ASD prevalence, from 4.2 per 1,000 in 1996 to 15.5 per 1,000 in 2010. [57] Likewise, increases in ASD prevalence have been reported based on special education Autism eligibility counts and systems using clinical diagnoses of developmental conditions.[58–62] Studies using administrative health databases such as insurance claim databases and hospital discharge, which are considered more efficient, have supported the studies that have found an increase in ASD prevalence.[63–66]

Significant variations in ASD prevalence adds to the complexity of ASD as a public health problem. The ADDM Network data has shown that prevalence of ASD varied by sex, with a male-to-female prevalence ratio of 4.5 (ranged from 3.6 to 5.1). In addition, there was also a geographic variation, ranging from 5.7 to 21.9 per 1,000 children in the US or from 1 in 175 children in Alabama to 1 in 45 children in New Jersey. Variation also occurred by race/ethnicity: white children had the highest prevalence compared to black and Hispanic with 15.8 per 1,000, 12.3 per 1,000 black and 10.8 per 1,000 Hispanic children, respectively.[5]

The most important characteristic of ASD diagnosis is perhaps age of diagnosis. The same study from the ADDM Network reveals that the median age of ASD diagnosis was older than age 4 years and varied by diagnostic subtypes, race/ethnicity and geographic areas. This CDC study also reports that the median age of ASD diagnosis was younger among white (52 months) than Hispanic children (56 months).[5] In addition, black children were reported to have their first evaluation at older age than white children. Race differences were also reported in a previous study involving Medicaid-eligible children: African American and Latino children were diagnosed 1.4 to 2.0 years later than white children.[54] The average age of ASD diagnosis among Medicaid-enrolled children was 64.9 months. [67] As being suggested from CDC, the results of these estimates are based on study objects and locations, and do not represent the entire population of children in the United States.

The increased number of ASD cases has been driven by a variety of factors, such as an improved ascertainment, broadened diagnostic criteria and an increase in risk factors.[68–72] Almost all previous studies have concluded that most of the upward trend in ASD prevalence can be accounted for by methodological factors such as changes in diagnostic criteria and better sampling procedures. Further, awareness among parents, professionals, and the general public regarding the existence of ASD has increased interest in participating in surveys and resulting in identifying more children with ASD.[73–75]

1.4. Autism Spectrum Disorder in At-Risk Children

While prevalence studies on ASD have been widely conducted, very limited research has examined at risk populations such as young children in early intervention programs (EIPs). It is estimated that approximately one-third of young children with ASD enroll in EIPs in the US thus, prevalence estimate in this subset of individuals may not be generalized as population-based estimation.[76] Generalizability may be also limited due to a significant refusal rate among at-risk children for ASD evaluations in EIPs.[77,78] However, it is noteworthy to examine prevalence of ASD in this population given they already experience developmental delays. From a practical standpoint, an improved understanding of ASD prevalence in at-risk children would be helpful for clinicians who need to determine diagnoses for these children.

Perhaps the most significant impact on tracking prevalence in EIPs are financial and policy implications. It has been estimated that intensive behavioral intervention costs for children with ASD such as Applied Behavior Analysis (ABA) or Early Intensive Behavioral Intervention (EIBI), can range from $40,000 to $60,000 per year.[79] Centers for Medicare and Medicaid Services (CMS) have clarified that ABA therapy may be covered under Medicaid waivers and Medicaid state plans. Since ASD is not required to receive early intervention services, these children may be found eligible due to social/behavioral impairment or delay and speech/ communication impairment. Not having ASD diagnosis may result in not having specific ASD treatments; therefore, it is important to have ASD diagnosis while in EIP to ensure that these children receive their ASD specific-treatments as early as possible.

One study conducted within a state-wide early intervention program in Louisiana (*EarlySteps*) found that prevalence of ASD was 30.14% (301 per 1,000 children), much higher compared to studies using clinical or community samples.[68] The Louisiana study is the only study published to date regarding ASD prevalence in at risk children. This study looked at ASD prevalence and its change overtime in the New York State Early Intervention Program (NYSEIP) to better understand ASD prevalence in children enrolled in the NYSEIP.

1.5. New York State Early Intervention Program

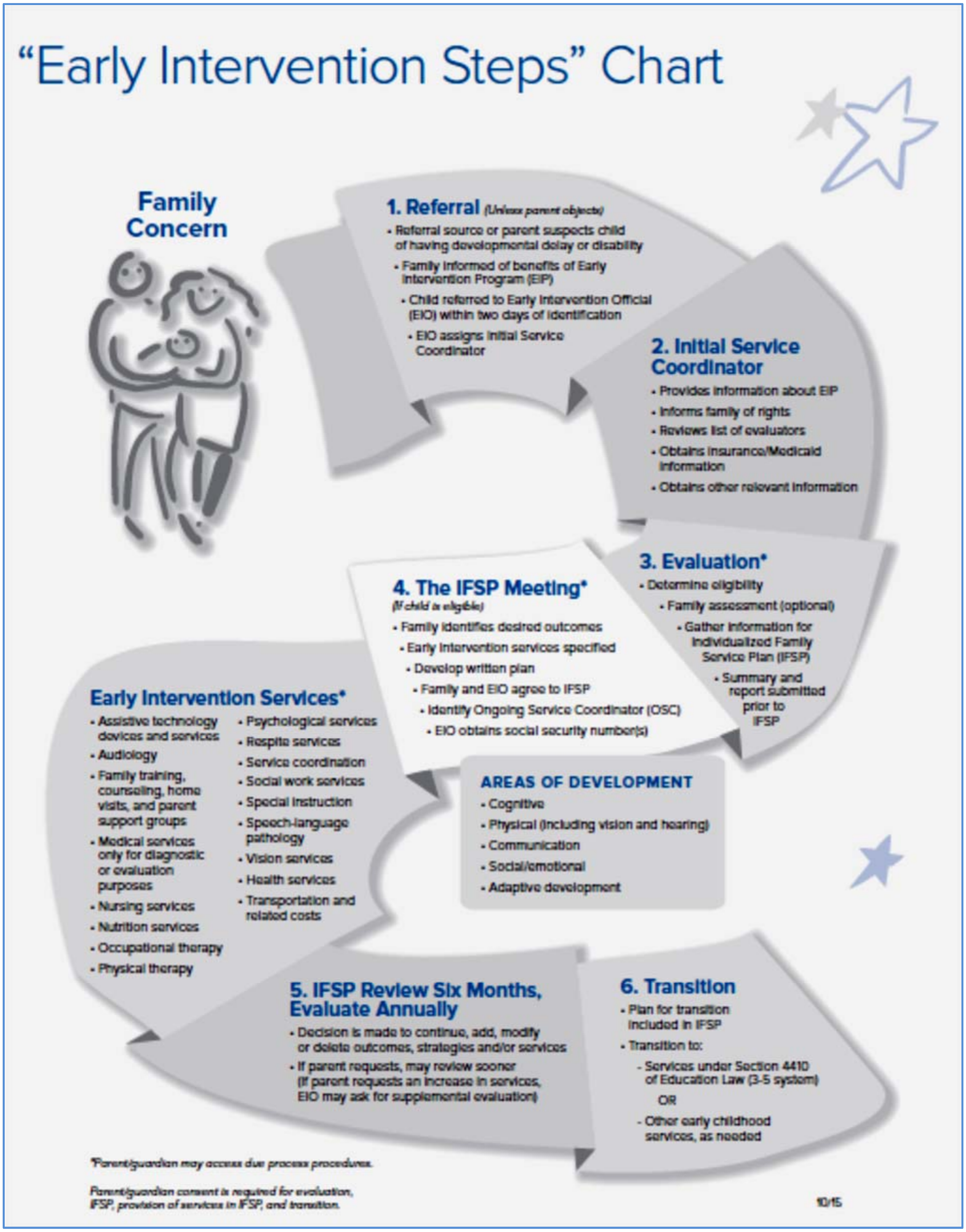
The New York State Early Intervention Program (NYSEIP) is part of the national Early Intervention Program for infants and toddlers with disabilities and their families which was enacted by Congress in 1986 under the Individuals with Disabilities Education Act (IDEA). The NYSEIP is administered by the New York State Department of Health through the Bureau of Early Intervention. In New York State, the Early Intervention Program was established in Article 25 of the Public Health Law and has been in effect since July 1, 1993.[35]

To be eligible for services, children must be under three years of age and have a confirmed disability or established developmental delay, as defined by the State, in one or more of the following areas of development: physical, cognitive, communication, social-emotional, and/or adaptive. The mission of the Early Intervention Program is to identify and evaluate as early as possible those infants and toddlers whose healthy development is compromised and provide for appropriate intervention to improve child and family development.[35,80]

Public Health Law (PHL) (Section 2542 .1. a) requires Early Intervention Officials (EIOs) to identify and locate children who are eligible for the Early Intervention Program and to provide for the identification, screening, and tracking of children at risk for developmental delay. PHL and regulations further require primary referral sources (parents or pediatricians) to refer children suspected of having disabilities, or at risk of having disabilities, to the EIO of the municipality in which the child resides (unless the child has been referred or the parent objects to the referral). Parents may also refer their child directly to the NYSEIP if they have a concern about their child's development, or when they agree with a concern raised by someone else about their child. Any child who meets risk criteria established in New York State regulations must be referred to the NYSEIP for developmental surveillance (screening and tracking). The purpose of developmental surveillance is to identify potential delays or disabilities, as early as possible, in children who are typically developing but are at high risk for developmental problems due to medical/biological neonatal or medical/biological post-neonatal and early childhood risk factors. Developmental surveillance, which may include developmental screening (a brief assessment procedure to identify children who should receive more intensive diagnosis or assessment), for these children is generally accomplished through their primary health care providers. When families cannot be engaged with a primary health care provider, municipalities may directly provide developmental screening.[35]

State and federal law and regulations require that children who are referred to EIOs with a confirmed or suspected disability are entitled to receive a comprehensive, multidisciplinary evaluation to determine whether they meet the eligibility criteria for the NYSEIP. “For children with a confirmed disability (i.e., a diagnosed condition with a high probability of developmental delay), the purpose of the multidisciplinary evaluation is to confirm the diagnosis through a review of appropriate medical or other child records, with parent consent; and, to conduct an evaluation and assessment of all developmental domains to assist in development of the Individualized Family Service Plan (IFSP). Upon receipt of a referral for a child with a suspected or confirmed disability, the EIO must promptly designate an initial service coordinator to assist the child's parent(s) in selection of an evaluator to conduct a multidisciplinary evaluation”.[36]

To summarize, the early intervention steps in NYSEIP are described in the following diagram.[81]



“Early Intervention Steps” Chart

Family Concern

1. Referral *(Unless parent objects)*

- Referral source or parent suspects child of having developmental delay or disability
- Family informed of benefits of Early Intervention Program (EIP)
- Child referred to Early Intervention Official (EIO) within two days of identification
- EIO assigns Initial Service Coordinator

2. Initial Service Coordinator

- Provides information about EIP
- Informs family of rights
- Reviews list of evaluators
- Obtains insurance/Medicaid information
- Obtains other relevant information

3. Evaluation*

- Determine eligibility
- Family assessment (optional)
- Gather information for Individualized Family Service Plan (IFSP)
- Summary and report submitted prior to IFSP

4. The IFSP Meeting*
(If child is eligible)

- Family identifies desired outcomes
- Early Intervention services specified
- Develop written plan
- Family and EIO agree to IFSP
- Identify Ongoing Service Coordinator (OSC)
- EIO obtains social security number(s)

Early Intervention Services*

- Assistive technology devices and services
- Audiology
- Family training, counseling, home visits, and parent support groups
- Medical services only for diagnostic or evaluation purposes
- Nursing services
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services
- Respite services
- Service coordination
- Social work services
- Special instruction
- Speech-language pathology
- Vision services
- Health services
- Transportation and related costs

AREAS OF DEVELOPMENT

- Cognitive
- Physical (including vision and hearing)
- Communication
- Social/emotional
- Adaptive development

5. IFSP Review Six Months, Evaluate Annually

- Decision is made to continue, add, modify or delete outcomes, strategies and/or services
- If parent requests, may review sooner (If parent requests an increase in services, EIO may ask for supplemental evaluation)

6. Transition

- Plan for transition included in IFSP
- Transition to:
  - Services under Section 4410 of Education Law (3-5 system)

  OR
  - Other early childhood services, as needed

**Parent/guardian may access due process procedures.*

Parent/guardian consent is required for evaluation, IFSP, provision of services in IFSP, and transition.

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Figure 1.1. Early Intervention Steps in New York State Early Intervention Program (*Source: New York State Department of Health, https://www.health.ny.gov/publications/0532/docs/chart.pdf*)

1.6. Significance of the Problem

ASD is an urgent public health concern because of the tremendous increase in prevalence in the United States (US) and worldwide. Compared to other public health concerns, prevalence of ASD is higher than AIDS[82], diabetes[83] or childhood cancers[84]. The economic burdens associated with increasing prevalence of ASD have been gradually increasing and adversely impacting affected families and communities.[13] Studies have indicated that more efforts are needed to improve early diagnosis and intervention, which have been scientifically and empirically proven to effectively improve developmental outcomes and quality of life through symptom reduction and improvement in skills and ability.[27,85,86]

Because of its lifelong effects, ASD adversely impacts families and the nation's economy due to associated health care costs. Recent studies have estimated that the lifetime cost to care for one individual with ASD ranged from $1.4 to 2.4 million or about $61 to $66 billion for an entire birth cohort of children with ASD in the US.[13] Costs of individuals with ASD result from direct (including medical cost) and indirect costs such as lost productivity of both individuals with ASD and their parents.[14] Annual medical expenditure for those with ASD was estimated range from $4,110 to $6,200 per year or 4.1-6.2 times greater than for those without ASD.[15] Similar costs were identified for Medicaid-enrolled children with ASD had six times higher the average annual medical costs for children without ASD.[87] The other study using Medicaid data from 42 states reported a higher total ASD-associated health care expenditure ($22,772) and had the largest rate of increase of all the mental disorders studied, because of a much higher rate of increase in the ASD prevalence. [88] Persistent stressful conditions for parents or caregivers has been profoundly shown to affect the well-being of the entire family.

State early intervention programs (EIPs) under the Individuals with Disabilities Education Act (IDEA) are the front-line service delivery systems for infants and toddlers with disabilities and serve an increasing number of children with ASD. In the 2013-14 program year, the NYSEIP provided services to 8,603 young children diagnosed with ASD and their families at a cost of nearly $232 million. There was a greater than fourfold increase in the number of ASD children and costs, compared to services to 2,458 children at cost of $57 million in the 2003-04 program year.[89] The federal laws require that EIP assessment should not be racially or culturally discriminatory.[90] The NYSEIP must provide non-discriminatory process of eligibility, services identified in the IFSP and work to improve outcomes for children with ASD.

Not all states including New York State collect data to report population-based prevalence of ASD. Identification and intervention would be more successful when health resources can be both effectively and efficiently allocated. This study described trends and assessed characteristics of children with ASD enrolled in the NYSEIP and examined differences among sub-groups. An analysis of the trends and characteristics of eligible children with ASD has not been published in a peer-reviewed journal to-date. As reported by other studies, there have been differences of age at diagnosis associated with gender, race/ ethnicity, parental socio-economic status, families' location of residence and ASD subgroups.

This study also examined socioeconomic characteristics related to age at diagnosis of ASD among eligible children in the NYSEIP and examined trends over time. A systematic evaluation of age and timing related to services for children with ASD after diagnosis has never been published in a peer-reviewed journal by the NYSEIP. An updated evaluation of age at ASD diagnosis, age of referral, timing related to early intervention services such as time to ASD evaluation and time to ASD diagnosis may provide needed direction and guidelines to clinicians and policy makers.

1.7. Specific Aims

The specific aims of this dissertation are:

1. To examine trends in prevalence and characteristics of autism spectrum disorder (ASD) among at risk children in New York State.
    1.1. To assess prevalence and trends of ASD among eligible children in the New York State Early Intervention Program, from 2005 to 2014.
    1.2. To examine sociodemographic characteristics (gender, race/ethnicity, insurance status and geographic location) of eligible children diagnosed with ASD in in the New York State Early Intervention Program, from 2005 to 2014.
2. To describe timing of autism spectrum disorder diagnosis by children's socio demographic characteristics of children enrolled in New York State Early Intervention Program.
    1.1. To describe age at ASD diagnosis of eligible children in the New York State Early Intervention Program
    1.2. To describe age at referral, time of evaluation and time of ASD diagnosis among eligible children diagnosed with ASD in the New York State Early Intervention Program

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CHAPTER 2.

TRENDS IN PREVALENCE AND CHARACTERISTICS OF CHILDREN WITH AUTISM SPECTRUM DISORDER ENROLLED IN THE NEW YORK STATE EARLY INTERVENTION PROGRAM, FROM 2005 TO 2014

2.1. Abstract

Background: Prevalence of autism spectrum disorder (ASD) has increased rapidly with well-documented disparities among demographic groups. However, few studies have investigated ASD prevalence in at-risk children. The objectives of this study were to examine the trend of ASD prevalence diagnosis among children 0-36 months who were enrolled in the New York State Early Intervention Program (NYSEIP) and to identify characteristics of children diagnosed with ASD in NYSEIP.

Methods: Data from NYSEIP were used to calculate annual prevalence of ASD by dividing the number of prevalent cases of ASD identified in the NYSEIP system by the total number of eligible children enrolled in the NYSEIP in a given referral year. Trends in ASD and the change of prevalence over time were examined using log-binomial regression. Chi-square statistics were used to compare distributions of selected characteristics for children with and without ASD.

Results: The overall estimated prevalence of children diagnosed with ASD who enrolled in NYSEIP was 77.3 per 1,000 children and increased significantly from 42.5 per 1,000 children (one in 24) in 2005 to 114 per 1,000 children (one in 9) in 2014. In general, there were upward trends in the prevalence of ASD in all sub-groups over the study period, with a different pattern of prevalence between New York City and the Rest of the State. Significant differences between children with and without ASD diagnosis were observed for all characteristics examined including social emotional area and developmental delay score, but not insurance status.

Conclusion: Prevalence of ASD diagnoses have been increased among children who were enrolled in the NYSEIP. The increases is comparable to national trends. Monitoring ASD trends is important for the effective and efficient planning for programs such as the NYSEIP.

2.2. Background

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by social and communication impairment and by certain restrictive and repetitive behaviors.[1] This lifelong condition has become one of the most prevalent diseases with a very rapid increase of total cases in the last 40 years.[2] National surveillance systems as well as global studies have reported substantial increases in the estimated prevalence of ASD diagnoses across demographic groups.[3–19]

The Centers for Disease Control and Prevention (CDC) reported an increase of over 117 % in ASD prevalence among children aged eight years-old since 1990s.[20] Increases in ASD prevalence have also been reported in other prevalence studies. National Health Interview Survey (NHIS), US survey data between 1997 and 2008, based on parental report, indicated a 289% increase in autism, the highest increase when compared to other developmental disabilities. Similarly, a population-based developmental disabilities surveillance program for eight year-olds in metropolitan Atlanta reported a 269% increase in ASD prevalence, from 4.2 per 1,000 in 1996 to 15.5 per 1,000 in 2010. [21] Comparable increases in ASD prevalence have also been reported from data using special education autism eligibility counts and systems using clinical diagnoses of developmental conditions.[6,22–25] The increasing prevalence of ASD requires continued monitoring of the trends in the population in order to enhance understanding of the risk factors, etiology and effectiveness of interventions. [26,27] Allocation of community resources including health, education and other related-sectors can be evaluated when prevalence of ASD and its trends are continually measured.[28]

Studies have demonstrated that there are some discrepancies in terms of age at diagnosis, gender, race/ ethnicity, socioeconomic status and geographic distribution[3,29–35] Examining ASD trends including children's characteristics is critical to evaluate programs that serve children with ASD and their families to ensure equity across population. Despite the continuity and completeness of the data on ASD in the United States, not all states including New York State have mandated reporting.

The latest report from a national surveillance system indicated that the prevalence of ASD among study sites was about 14.7 per 1,000 and marked by significant variations in ASD prevalence by age, sex, race/ethnicity, socioeconomic status and geographic area.[2] With the comprehensive method used by Autism and Developmental Disabilities Monitoring (ADDM) Network, findings from the largest ongoing ASD tracking system in the US provided updated population-based estimates of the prevalence of ASD in their 11-study site. This figure has dramatically increased in the last two decades, 6.7 per 1,000 (one in 150) in the Network's 2000 surveillance year to 14.7 per 1,000 (one in 68). [2,26] Studies using administrative health data, such as insurance claim and hospital discharge databases which are considered more efficient [36–38], have supported the fact that ASD has become more prevalent. [39,40]

The etiology of ASD is still unknown[41,42]. Scientific and empiric evidence has identified better outcomes when high quality evidence-based interventions start at a young age. Studies have suggested that children who begin treatment at an earlier age have better outcomes than those who initiate treatment later.[43–45] Therefore, early identification has been found to be important. Early intervention has been shown to improve the quality of affected family or caretaker's life and society as a whole.[46–49] Research has demonstrated that early intervention for children with ASD significantly improves brain structure and function which is the key for optimizing outcomes for children with ASD[44,50], particularly for cognitive improvement, social interaction enhancement and communication development [51–53].

Most of the prevalence studies were conducted using general population samples and very limited research considered at risk population such as young children in early intervention programs (EIPs). It is estimated that prevalence of ASD among young children with ASD enrolled in EIPs is higher than among a community sample of toddlers. Generalizability to the overall population may be impacted by the significant refusal rate to public programs such as EIPs among at-risk children.[54] It is important to examine the prevalence of ASD in EIP since the children have an identified developmental delay and may be more likely to have ASD than the general population.

State EIPs under the Individuals with Disabilities Education Act (IDEA) are the front-line service delivery systems for infants and toddlers with disabilities and serve an increasing number of children with ASD. In the 2008-09 program year (July 1-June 30), the New York State Early Intervention Program (NYSEIP) provided services to 4,486 young children diagnosed with ASD and their families at a cost of nearly $90 million. As of the 2013-4 program year, the number of children with ASD served by the NYSEIP has increased to 8,603 children at a cost of more than $230 million.[55] The federal and state laws require that EIP assessment should not be racially or culturally discriminatory.[56] In addition, studies have shown that effective early intervention programs for children with ASD need to be developmentally appropriate to ensure the best opportunity for achieving optimal developmental outcomes. The NYSEIP must provide a non-discriminatory process to determine a child’s eligibility for the program and provide the services agreed upon in the Individualized Family Service Plan (IFSP).

The objectives of this study were to examine the trend of ASD prevalence among children 0-36 months enrolled in the NYSEIP as well as to investigate the trends by sociodemographic characteristics associated with ASD diagnosis such as gender, race/ethnicity, insurance status (including Medicaid and private insurance) and geographic location.

2.3. Methods

Data source

The data were from the information systems for the administration of the Early Intervention Program at the New York State Department of Health. Two data systems were used: New York Early Intervention System (NYEIS) and Kids Integrated Data System (KIDS). NYEIS is a centralized, web-based, state-of-the-art system that electronically manages the NYSEIP administrative tasks and provides for information exchanges. This system is designed to support the NYSEIP's service delivery, financial, administration, and management activities at both the local and state levels. These activities include initial intake, evaluation, eligibility determination, IFSP development, service provision, and all financial aspects including insurance, claims, payments, and Medicaid reimbursement. From 2010-2015, KIDS was gradually replaced by NYEIS.

The study protocol and all analyses were reviewed and approved by the Institutional Review Board at the University at Albany, State University of New York and New York State Department of Health. All data were de-identified prior to analysis.

Study Population

A total of 303,389 eligible children (age 0-36 months) from January 1, 2005 to December 31, 2014 were included in the analysis. These children represented 55.6 % of the total number of children referred to the NYSEIP in the study period. Children with ASD were defined as those with a documented diagnosis using International Classification of Diseases (ICD 9) and ICD 10.

The ICD 9 code is used for diagnoses made before 2014 which includes autistic disorder or infantile autism (code 299.0), Asperger's disorder (code 299.80), and pervasive developmental disorder and not otherwise specified or PDD-NOS (code 299.90). The ICD 10, which is used at beginning of 2014, includes autistic disorder and infantile autism (code F84.0), Asperger's syndrome (code F84.5), other pervasive developmental disorders (code F84.8) and pervasive developmental disorder, unspecified and atypical autism (code F84.9). The number of children with ASD was 23,502 or 8.2% of all eligible children.

Data Analysis

Demographic variables pertaining to the affected child were extracted from the NYSEIP data systems. These included gender, race/ ethnicity, insurance status and geographic locations. Variables were selected based on the results of previous studies and their availability and/or completeness in the NYSEIP database. Missing data on each variable per year were less than 5%; therefore, they were categorized as missing completely at random (MCAR) and not included in the analysis.

Frequencies and percentages were used to describe study population characteristics for each year in the study period. The estimates of annual prevalence were obtained by dividing the number of prevalent cases of ASD identified in NYSEIP systems by the total number of eligible children enrolled in the NYSEIP in a referral year. The annual prevalence was also calculated by gender, race/ethnicity, insurance status (‘yes’ if the child had either Medicaid or private insurance and ‘no’ if no insurance was recorded), type of insurance: Medicaid or private insurance for those with insurance and locations. The results of calculations of ASD prevalence by counties were mapped using the GIS program: ArcMap 4.0.

The average annual prevalence or crude prevalence was estimated as the sum of numerators across referral years divided by the sum of denominators across all applicable referral years. Prevalence change was estimated as the percentage difference between prevalence in the last study year and the first study year. Analyses were performed in SAS software version 9.4 (SAS Institute, Cary, NC).

Log-binomial regression models were used to analyze the trends in prevalence over time for each variable. The dependent variable was ASD prevalence, and the categorical predictor variables were entered for the year (2005 as the reference), gender (female as the reference), race/ethnicity (non-Hispanic white as the reference), insurance status (had no insurance as the reference), Medicaid status (had no Medicaid as the reference) and private insurance status (had no private insurance as the reference), Rest of the State (ROS) as the region’s reference and Capital Region as the regional’s reference.

The analyses were further stratified by region of New York City (NYC) and ROS, with the same dependent variables. The effect of the interaction between variables and time was then examined by multiplying the predictor variables with the time variable (referral year) to investigate whether the change of prevalence over time differed across each predictor category. A statistically significant interaction between time and a given variable of interest indicated that the change in prevalence differed over time compared with the variable reference.

2.4. Results

Population characteristics

The eligible children enrolled in the NYSEIP from 2005 to 2014 included in the study was about 55.6% of the total children who were referred (546,203 children) for those years (Table 2.1). The proportion of the population of these eligible children within categories were mostly stable during the study period. The proportion of males was 65.4%. During this period, non-Hispanic white was the race with the highest proportion (48.1%) of children enrolled in the NYSEIP. Total insured children were about 75%. The largest percentage of children were from NYC (53.3%) and the Metropolitan Area Region (25.9%).

Overall ASD Prevalence

A total of 23,502 (77.3 per 1,000 eligible children) had ASD diagnosis in the NYSEIP (Table 2.2). Within the NYSEIP, ASD prevalence among children 0-36 months was 93 per 1,000 (one in 11) boys and 47.6 per 1,000 (one in 22) girls. The overall prevalence ratio for boys compared with girls was 2.0 (95% CI: 1.9-2.0; p<.0001). Estimated prevalence among non-Hispanic white children (54 per 1,000 children) was significantly lower than it was among non-Hispanic Asian children (132.5 per 1,000; PR: 2.4, 95% CI: 2.3-2.6, p<.0001), Hispanic children (106.4 per 1,000; PR: 2.0, 95% CI: 1.9-2.0), p<.0001), and non-Hispanic black children (104.2 per 1,000; PR: 1.9, 95% CI: 1.9-2.0), p<.0001).

Total number of insured-children with ASD diagnosis was more than five times than children with no documented insurance, but the estimated prevalence among children with insurance (either Medicaid or private insurance) was similar to those without documented insurance. Estimated prevalence of ASD among children with Medicaid was 78.8 per 1,000 children that compared to children who did not have Medicaid (75.6 per 1,000; PR: 1.0).

During the study period, the prevalence ratio for children who lived in NYC compared with those who lived in ROS was 2.4. Estimated prevalence among those who lived in the Capital Area Region (50 per 1,000 children) was significantly lower than it was among children who lived in the Metropolitan Area Region (57.5 per 1,000; PR: 2.6). High ASD prevalence is found in all boroughs within NYC compared to ROS (Figure 2.1).

Trends in ASD Prevalence

There was a markedly upward trend in prevalence of ASD among eligible children in the NYSEIP from 2005 to 2014. Estimated prevalence of ASD among eligible children in NYSEIP increased significantly from 42.5 per 1,000 (one in 24) children in 2005 to 114 per 1,000 (one in 9) children in 2014 (Table 2.3). This represents an annual change of 7.7% and an absolute prevalence change of 178.9%.

In general, the prevalence of ASD increased significantly in all sub-groups over the study period. Prevalence was significantly higher among boys than among girls, ranging from 33.9 per 1,000 boys (one in 30) in 2005 to 91.4 per 1,000 boys in 2014. In 2014, approximately one in 11 boys had ASD compared with one in 37 girls (Figure 2.2). Significant interactions in the annual prevalence were observed between year and male sex ($p<.0001$) (Table 2.3).

Prevalence of ASD was higher among non-Hispanic whites in 2005 (24.3 per 1,000) compared to other race/ ethnic group, until 2008 where prevalence of ASD among Hispanic children started to sharply increase from 19.3 per 1,000 children in 2008 to 44.5 per 1,000 children in 2014 (Figure 2.3). Absolute change of ASD prevalence among non-Hispanic whites was the smallest (56.4%) compared to other races (Table 2.3). Significant increases of ASD prevalence during the study period were found for non-Hispanic Asian, non-Hispanic black and non-Hispanic other race. Significant interactions in the annual prevalence were observed between year and all races, except American Indian and non-Hispanic other races.

ASD prevalence in NYC among non-Hispanic blacks increased with more than 600% compare to 159 % increase among non-Hispanic whites, 269% increase among non-Hispanic Asian and 369% among Hispanic children. In ROS, the prevalence of ASD among Hispanic children increased the most with 245% absolute change, compared to 11-12% increase among non-Hispanic white or non-Hispanic black, and 27% absolute change among non-Hispanic Asian.

Prevalence of ASD increased greatly among those with insurance, either Medicaid or private insurance. Prevalence of ASD among children with Medicaid was lower than it was among those without Medicaid in 2005 (16.7 per 1,000 and 25.8 per 1,000, respectively). However, the prevalence of ASD among children with Medicaid was higher starting in 2008 compared to non-Medicaid children. At the same time the ASD prevalence among children with private insurance started to sharply increase. There was about a threefold higher prevalence of ASD among children insured by Medicaid in 2014 relative to those not insured by Medicaid (Figure 2.4). Absolute changes of ASD prevalence for both subgroups were 35.3% and 288%, respectively.

There was about a threefold higher prevalence of ASD among children residing in NYC relative to those residing in ROS (Figure 2.5). The significant increases in ASD prevalence were seen in all regions except Capital Region (Figure 2.7). Given the significantly higher occurrence of ASD diagnoses among children in NYC, trend analysis of ASD prevalence were further stratified by region.

Stratifying into NYC and ROS, increases in ASD prevalence were seen for both sexes for children with ASD who resided in NYC (Table 2.4 and 2.5). There was a nearly fourfold higher prevalence of ASD among boys and more than six-fold higher prevalence of ASD among girls in NYC compared to ROS (Figure 2.7). Meanwhile, prevalence of ASD among children from the ROS increased significantly (absolute prevalence changes were 34.7% and 71.1 % for boys and girls, respectively) (Figure 2.11). There was a much higher increase in prevalence of ASD among all race-subgroups in NYC relative to those from ROS (Figure 2.8 and 2.9).

Characteristics of children with ASD

Significant differences were observed for all characteristics of children with versus without ASD (Table 2.6). The ratio of male to female among children with ASD was about 3:1 compared to 2:1 for children without ASD. The percentage of Hispanic and non-Hispanic white children were the largest among children with ASD (about 35% each). Children with ASD were significantly different than those without ASD in the social emotional functional areas (p=0.0210). In addition, children with ASD had more in developmental delays compared to those without ASD (Table 2.7).

Given the significantly higher occurrence of ASD diagnoses among children in NYC, characteristics of children with or without ASD were further stratified by region (Table 2.8). Most of the characteristics were similar with the state level analyses, except in ROS, non-Hispanic white children were the greatest proportion (65%) among those with ASD (Table 2.7). In addition, the proportions of ASD child among non-Medicaid children and Medicaid children in ROS were 56.8% and 31.3%, respectively. ASD diagnosis among non-Hispanic white children accounted for 24.9% in NYC compared with those in ROS in which non-Hispanic white children had greatest proportion of ASD cases.

2.5. Discussion

The study's findings indicate that one in 13 eligible children enrolled in the NYSEIP between 2005 and 2014 were diagnosed with ASD by 36 months of age (77.3 per 1,000 children). The ASD prevalence in this study is smaller compared to a study conducted in the Louisiana's EIP[57], which found a total of 611 toddlers out of 20,127 had a diagnosis of for a ASD or prevalence of 301.4 per 1,000 children. Using the same diagnostic criteria, the Louisiana study employed a licensed clinical psychologist to make the ASD diagnosis while this study used existing administrative information from the NYSEIP database.

Estimated ASD prevalence in this study was two times higher among boys than among girls. While there is no comparable study for gender differences in similar group of individuals, this finding can be compared to the recent updated surveillance estimates from the ADDM Network which found a higher estimated prevalence of ASD among boys than among girls (4.5 times higher) and the recent estimate based on the US households interview in the NHIS that prevalence of ASD among boys was significantly higher than among girls aged 3-17 years (3 times higher).[26,58]

The prevalence of ASD was 140% higher among non-Hispanic Asian compared to non-Hispanic white, 90% smaller among non-Hispanic white compared with non-Hispanic black children, 40% smaller among non-Hispanic white compared with American Indian children and 100% smaller among non-Hispanic white compared with Hispanic children (Table 2.2). In contrast with this finding, the ADDM Network study indicated that non-Hispanic white children had a higher documented prevalence of ASD compared to other races.

Prevalence of ASD among children residing in NYC was 140% higher compared with children whose parents lived in ROS. Children in the Western Region had nearly four times the prevalence of ASD as children in Capital Region. The Metropolitan Area Region had the highest prevalence of ASD compared with other regions in ROS, about three times higher than among children in Capital Region. There was a similar ratio ASD prevalence between Medicaid and non-Medicaid children, with slightly higher prevalence of ASD among those with Medicaid.

The upward trend of ASD prevalence was observed in children enrolled in the NYSEIP from 2005 to 2014. This finding is consistent with previous studies that suggest ASD prevalence among children is increasing. Increases in ASD prevalence during the mid-1990s and continuing through the late 2000 have been noted in a number of studies using varying definitions of autism and study designs. Not many studies have been focusing on trends in ASD prevalence for children 0-36 months. Studies with a population similar with this study were the 2001-2005 Massachusetts Pregnancy to Early Life Longitudinal (PELL) data system [59] study and the New York City Longitudinal Study of Early Development (LSED)[60]. Both studies used data on children enrolled in the EIP as the numerator and total population of 0-36 months as the denominator- to calculate incidence (PELL study) and prevalence (LSED study) of ASD. For the Massachusetts PELL, ASD incidence increased from 5.6 per 1,000 children (one in 178) for 2001 birth cohort to 9.3 per 1,000 (one in 108) for the 2005 cohort. For the NYC LSED study, prevalence of ASD increased from 0.3 per 1,000 children (one in 3,300) for the 1994 birth cohort to 4.3 per 1,000 children (one in 233) for 2001 birth cohort. These studies compared the total ASD children in EIP with total population, a much lower prevalence of ASD than this study is expected.

The observed increase of ASD prevalence in this study reveals that ASD prevalence increase from 42.5 per 1,000 (one in 24) in 2005 to 114 per 1,000 (one in 9) in 2014. The absolute change of 178% from this study is much lower than absolute change in ASD prevalence from the NYC LSED study (1333% change). Since EIP is not a population-based program, comparing number of ASD cases in this program with population estimates is not appropriate. This study did not use total population as the denominator.

The prevalence of ASD increased among children from most of the geographic locations in New York State. The prevalence of ASD has been reported to vary based on locations and demographic groups. Corresponding with other studies, this study is a complement of capturing the disparities in ASD prevalence. Population-based estimates of ASD prevalence in the United States are reported by three CDC surveys: the ADDM Network, NHIS and the National Survey of Children's Health (NSCH). Taken as a whole, studies using different methodologies and in different populations have reported converging estimates for ASD prevalence in the United States as well as other countries.

The observed increased within the 10-year period might reflect the success of national efforts such as the campaign promoted by the CDC: "Learn the Signs, Act Early" and the recommendation of American Academy of Pediatrics (AAP) with regard to ASD screening among providers. Increasing awareness about autism among providers and general people as the result of increased media attention and advocacy efforts is considered a substantial contributing factor to the increasing prevalence of ASD. Although the precise reason is still unidentified, ASD diagnoses are escalating nationally and globally.

Early identifications of ASD is the priority of the US Department of Health and Human Services' Healthy People 2020 goal of increasing the proportion of children with ASD having a first evaluation by 36 months of age by 10%.[61] Lowering the age at first evaluation is important because when impairments are identified through a comprehensive evaluation, referrals for specific services can be made, often without a formal diagnosis. Based on evidence linking early treatment to improved outcomes, it is important that children with developmental concerns be evaluated and referred to services as soon as possible. The baseline of Healthy People 2020 goal is 42.7 percent of children aged 8 years with ASD had a first evaluation by 36 months of age using the CDC finding reported in 2006. Comparing children in this study who were evaluated and received their

ASD diagnosis before their three birthday, New York State has been showing an increasing proportion of ASD first evaluation more than 10%, from 42.7 % in 2005 to 118% in 2014.

Several of the findings regarding the trend analysis and descriptive characteristics of children with ASD were noteworthy. While race discrepancy was still observing in this population, the high increases in some minority groups suggest that efforts on targeting these communities for autism awareness and identification have been successfully tailored. Findings of this study also suggest that although such differences still there, the gaps are closing. Factors such as language barriers, lack of access to services and health insurance coverage may still contribute to this disparity. Another finding is about gender disparities. The predominance of boys with ASD in most ASD studies also was remarkable. This study shows the narrow gaps among genders, which may indicate a removal of an historic bias towards men and boys in the diagnostic criteria for autism.

This is the second study to date studying ASD prevalence in a pooled high-risk child population but the first one with measures over 10-year period. By examining this group of children, this study is most likely capturing the most serious cases on the autism spectrum. The implication of having ASD diagnosis is the opportunity to receive Applied Behavior Analysis (ABA) or Early Intensive Behavioral Intervention (EIBI). This service's cost is estimated to range from $40,000 to $60,000 per year and may be covered under Medicaid waivers and Medicaid state plans. With the current trend, it is expected that the cost of ASD in the NYSEIP will much more increase.

One of the findings that may lead to future study is regarding the different prevalence by geographic region. Deeper investigation on factors such as the type of healthcare professionals making the diagnosis or how New York families access early screening and evaluation in each area may help answer the question on why the different prevalence and rate of changes between NYC and ROS as well as across counties exist. Since this study relied on administrative data, findings during the study period may have been a result of improvement in recording and reporting diagnoses by local providers. This is an important indication of better administrative and data systems by the NYSEIP, which also recommends greater attention to counties or regions with unusually low measurement of ASD prevalence. Future studies may clarify whether the trend increases or plateaus. Continued monitoring of ASD prevalence is important to evaluate the NYSEIP as well as the impact of the ASD definition change in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5).

This study has several limitations. The denominator for this study is eligible children in the NYSEIP and not the entire population. Therefore, this study may not be generalized as representative of New York State. Care should be used in interpreting the results as a reflection of at risk children in this age group of 0-36 months for two reasons. First, the participation in the NYSEIP is voluntary, not all children with developmental delay or ASD diagnosis enrolled in the NYSEIP. Second, studies show that the age-eligible population served in state EIPs ranging from 2% to 78% among states while the proportion of children served by state EIPs from 1.48% to 6.98%.[62] These results were specific to children from 0-36 months in New York State seeking public services and may not be generalized outside New York State or to children who have an ASD diagnosis after they left the NYSEIP. Data for these children (after the NYSEIP) were not available.

Another limitation is that ASD diagnosis were not independently confirmed. Reported ASD diagnoses were used. This study may underestimate the ASD prevalence since it used administrative data for case ascertainment. Incompleteness of data is expected in administrative data. However, missingness on each variable was less than 5% per year and categorized as MCAR. Additionally, this study is limited to selected characteristics collected as part of the NYSEIP and did not include other suspected ASD risk factors such as parental age, family history, other disorders, pregnancy history and certain environmental/ chemical exposures.[60,63–78]

Although there are limitations to using administrative data, the data are useful for assessing the number of children receiving ASD services and for monitoring trends. This study provides a trend analysis and prevalence ratio that is useful for the NYSEIP and is reflective of the national trends.

2.5 Conclusion

Approximately one in 13 eligible children enrolled in the New York State Early Intervention Program between 2005 and 2014 were diagnosed with autism spectrum disorder by 36 months of age (77.3 per 1,000 children). The upward trend of ASD prevalence was observed in children enrolled in NYSEIP from 2005 to 2014. The prevalence of ASD increased from 43 per 1,000 (one in 24) children in 2005 referral year to 114 per 1,000 (one in 9) children in 2014 referral year. The 178.9% increase in prevalence over the 10-year period represents a three-fold increase of children with ASD in 2014 compared to the number of children with ASD a decade earlier. This study shows a useful identification of trends and disparities in ASD diagnosis. These findings highlight that race disparity of ASD diagnosis has been narrowed which may indicate the success of efforts on targeting minority groups. The results of this analysis can be used to anticipate future service demands and resources needed for ASD specific interventions for at risk children in New York State. In addition, findings of this study can be used to increase local providers' awareness about identifying early signs of ASD.

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2.7. Appendix

Table 2.1a. Number and percentage of eligible children in NYSEIP, by selected characteristics, 2005-2014.

Characteristics	**Year of referral**											
	2005		**2006**		**2007**		**2008**		**2009**		**2010**	
	n	**(%)**	**n**	**(%)**	**n**	**(%)**	**n**	**(%)**	**n**	**(%)**	**n**	**(%)**
Sex												
Male	19,984	(64.7)	19,138	(65.1)	19,824	(65.3)	22,156	(65.1)	21,819	(65.5	20,521	(65.3)
Female	10,911	(35.3)	10,273	(34.9)	10,519	(34.7)	11,859	(34.9)	11,491	(34.5	10,908	(34.7)
Race												
Hispanic	4,486	(22.5)	6,228	(27.4)	6,980	(26.7)	7,960	(26.5)	8,638	(26.9	8,748	(28.1)
American Indian	26	(0.1)	43	(0.2)	49	(0.2)	47	(0.16)	51	(0.18	57	(0,18
Asian NH	976	(4.9)	1,248	(5.5)	1,421	(5.4)	1,718	(5.7)	1,876	(5.8)	1,789	(5.7)
Black NH	1,931	(9.7)	2,919	(12.9)	3,345	(12.8)	3,990	(13.3)	4,627	(14.4	4,532	(14.6)
White NH	12,467	(62.6)	12,240	(53.9)	14,282	(54.7)	16,251	(54.1)	16,647	(51.8	15,693	(50.4
Other	19	(0.1)	42	(0.2)	45	(0.2)	77	(0.3)	314	(1.0)	336	(1.1)
Insurance status												
Yes	36,765	(74.0)	38,635	(76.9)	41,396	(78.5)	45,376	(80.9)	46,573	(82.1	47,604	(82.0)
No	12,942	(26.0)	11,611	(23.1)	11,343	(21.5)	10,729	(19.1)	10,189	(17.9	10,440	(18.0)
Medicaid Status												
Yes	14,838	(47.9)	14,889	(50.5)	15,216	(50.1)	18,047	(53.0)	18,601	(55.8	18,375	(58.4)
No	16,111	(52.1)	14,573	(49.5)	15,147	(49.9)	15,998	(47.0)	14,742	(44.2	13,096	(41.6)
Private Insurance												
Yes	10,914	(35.3)	11,040	(37.5)	12,524	(41.3)	14,287	(42.0)	13,373	(40.1	11,823	(37.6)
No	20,035	(64.7)	18,422	(62.5)	17,839	(58.7)	19,758	(58.0)	19,970	(59.9	19,648	(62.4)
Residential												
New York City	18,258	(59.0)	17,064	(57.9)	16,279	(53.6)	18,053	(53.0)	17,581	(52.7	16,833	(53.5)
Rest of the state	12,691	(41.0)	12,398	(42.1)	14,083	(46.4)	15,991	(47.0)	15,762	(47.3	14,637	(46.5)
Total eligible children	30,949	(62.3)	29,462	(58.6)	30,363	(57.6)	34,045	(60.7)	33,343	(58.7)	31,471	(54.2)
Total referred children	49,707		50,246		52,739		56,105		56,762		58,044	

Table 2.1b. Number and percentage of eligible children in NYESEIP, by selected characteristics, 2005-2014.

Characteristics	**Year of referral**								**Total**	**%**
	2011		**2012**		**2013**		**2014**			
	n	**(%)**	**n**	**(%)**	**n**	**(%)**	**n**	**(%)**		
Sex										
Male	19,682	(65.9)	18,12	(66.1)	18,470	(66.1)	19,107	(65.6)	198,825	65.4
Female	10,181	(34.1)	9,278	(33.9)	9,491	(33.9)	10,003	(34.3)	104,914	34.5
Race										
Hispanic	8,006	(27.2)	7,547	(27.6)	7,544	(27.0)	7,820	(26.9)	73,957	24.3
American Indian	53	(0.2)	52	(0.2)	42	(0.15)	43	(0.2)	463	0.2
Asian NH	1,603	(5.4)	1,689	(6.2)	1,627	(5.8)	1,793	(6.2)	15,740	5.2
Black NH	4,276	(14.5)	3,170	(11.6)	2,995	(10.7)	3,055	(10.5)	34,840	11.5
White NH	14,862	(50.4)	13,97	(51.0)	14,644	(52.4)	15,176	(52.1)	146,236	48.1
Other	682	(2.3)	920	(3.4)	1,100	(3.9)	1,221	(4.2)	4,756	1.6
Insurance status										
Yes	43,814	(75.8)	38,61	(70.4)	35,856	(66.1)	34,356	(61,8)	165,671	74.9
No	13,977	(24.2)	16,27	(29.6)	18,426	(33.9)	21,274	(38.2)	137,202	25.1
Medicaid Status										
Yes	17,607	(58.9)	15,89	(58.0)	15,820	(56.6)	16,387	(56.3)	165,671	54.5
No	12,276	(41.1)	11,51	(42.0)	12,141	(43.4)	12,723	(43.7)	138,318	45.5
Private Insurance										
Yes	9,597	(32.1)	8,411	(30.7)	7,862	(28.1)	6,904	(23.7)	106,735	35.1
No	20,286	(67.9)	18,99	(69.3)	20,099	(71.9)	22,206	(76.3)	197,254	64.9
Residential										
New York City	15,382	(51.5)	13,81	(50.4)	14,287	(51.1)	14,620	(50.2)	162,175	53.3
Rest of the state	14,500	(48.5)	13,58	(49.6)	13,674	(48.9)	14,490	(49.8)	141,810	46.6
Total eligible children	29,883	(51.7)	27,402	(49.9)	27,961	(51.5)	29,110	(52.3)	303,989(55.6)	100
Total referred children	57,791		54,885		54,294		55,630		546,203	

Table 2. 2. Prevalence autism spectrum disorder among 1,000 eligible children in New York State Early Intervention Program, by selected characteristics, 2005-2014

Characteristics	**Total Eligible**	**Total No. with**	**ASD Prevalence per 1,000 children**		**Prevalence Ratio**	***p-value***
Sex						
Male	198,825	18,496	93.0	(91.8 – 94.3)	2.0 (1.9 – 2.0)	<.0001
Female	104,914	4,997	47.6	(46.3 – 48.9)	(ref.)	
Race						
Hispanic	73,957	7,872	106.4	(104.2 – 108.7)	2.0 (1.9 – 2.0)	<.0001
American Indian	463	34	73.4	(49.7 – 97.2)	1.4 (1.0 – 1.8)	0.0625
Asian NH	15,740	2,086	132.5	(127.2 – 137.8)	2.4 (2.3 - 2.6)	<.0001
Black NH	34,840	3,630	104.2	(101.0 – 107.4)	1.9 (1.9 - 2.0)	<.0001
White NH	146,236	7,891	54.0	(52.8 – 55.1)	(ref.)	
Other	4,756	481	101.1	(92.6 – 109.7)	1.9 (1.7 - 2.0)	<.0001
Insurance status						
Yes	257,502	19,859	77.1	(76.1 – 78.2)	1.0 (0.9 – 1.1)	0.3550
No	46,487	3,643	78.4	(75.9 – 80.8)	(ref.)	
Medicaid Status						
Yes	165,671	13,052	78.8	(77.5 – 80.1)	1.0 (1.0 – 1.0)	0.0009
No	138,318	10,450	75.6	(74.2 – 76.9)	(ref.)	
Private						
Yes	106,735	8,067	75.6	(74.0 – 77.2)	1.0 (0.9 – 1.0)	0.0086
No	197,254	15,435	78.2	(77.1 – 79.4)	(ref.)	
Residential						
New York City	162,175	17,305	106.7	(105.2 – 108.2)	2.4 (2.4 – 2.5)	<.0001
Rest of the state	141,810	6197	43.7	(42.6 – 44.8)	(ref.)	
Region						
-Capital Area	14,318	716	50	(46.4 – 53.6)	(ref.)	
-Central Region	17,784	270	15.2	(13.4 – 17.0)	0.7 (0.6 – 0.8)	<.0001
-Metropolitan	78,833	4536	57.5	(56.0 – 59.2)	2.6 (2.4 – 2.9)	<.0001
-Western Region	30,875	675	21.9	(20.2 – 23.5)	4.9 (4.5 – 5.3)	<.0001
TOTAL New York	**303,989**	**23,502**	**77.3**	**(76.4 – 78.3)**		

Figure 2. 1. Prevalence autism spectrum disorder among 1,000 eligible children in New York State Early Intervention Program 2005-2014, by counties

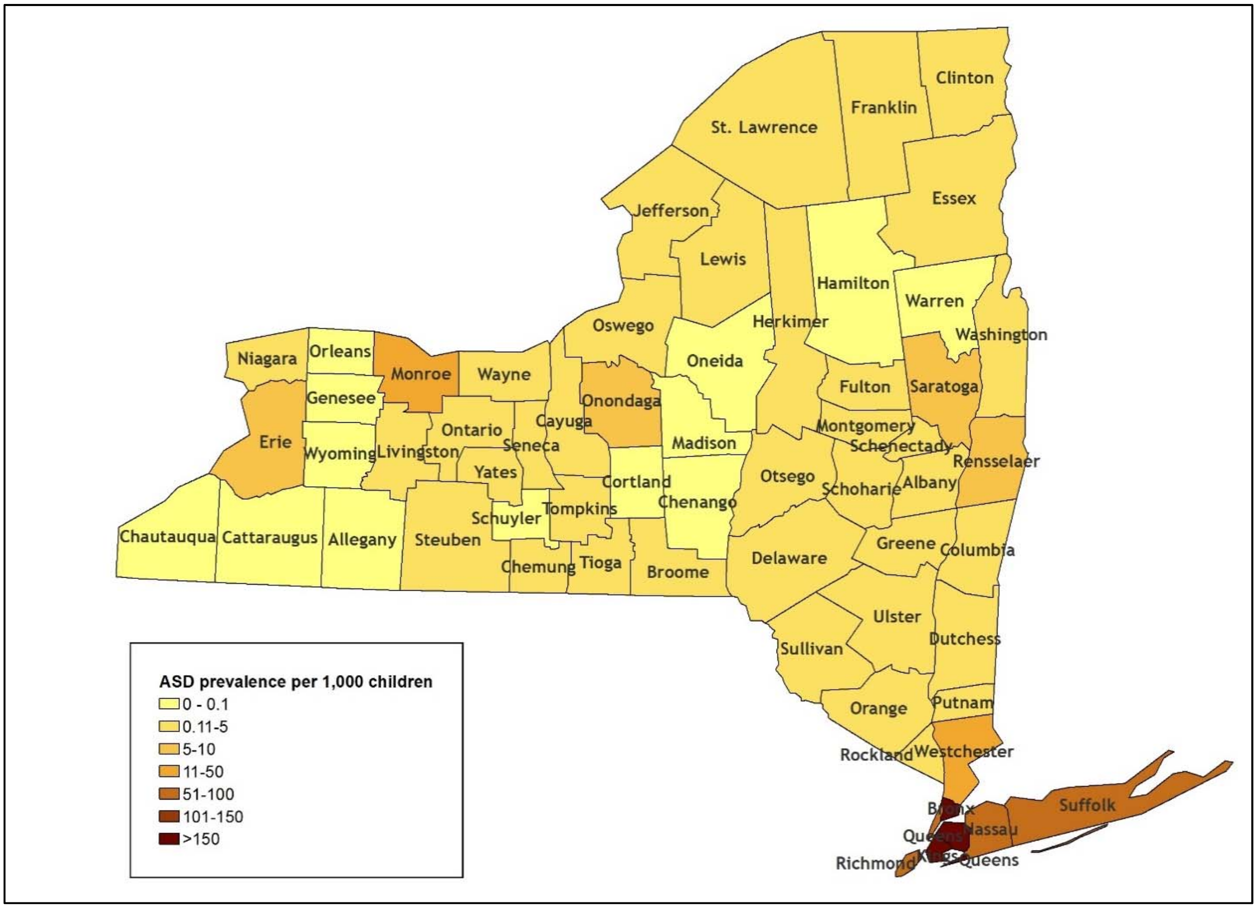

Table 2.3. Annual prevalence of autism spectrum disorder among 1,000 eligible children in New York State Early Intervention Program, by selected characteristics, 2005-2014 *(*p-value of interaction between variable of interest and referral year)*

Characteristics	**Year of referral**										***p-value****
	2005	**2006**	**2007**	**2008**	**2009**	**2010**	**2011**	**2012**	**2013**	**2014**	
Sex											
Male	33.9	39.2	45.8	48.8	54.1	61.1	66.9	85.7	90.0	91.4	<.0001
Female	8.7	8.7	11.4	12.5	14.0	16.6	19.7	24.8	23.3	27.4	(ref)
Race											
Hispanic	8.7	12.9	18.2	19.3	24.8	30.2	32.0	44.2	41.6	44.5	<.0001
American Indian*	0.1	0.1	0.1	0.0	0.2	0.1	0.2	0.2	0.2	0.1	0.4117
Asian NH	3.7	3.8	5.0	6.1	7.0	6.5	7.2	10.7	11.0	13.0	<.0001
Black NH	3.7	6.6	8.2	10.4	11.9	14.2	17.7	19.0	17.7	17.7	<.0001
White NH	24.3	21.8	25.3	25.4	24.6	26.4	27	33.2	38.1	38.0	(ref)
Other	0.2	0.1	0.1	0.1	0.3	0.4	2.3	3.4	4.7	5.4	0.0008
Insurance status											
Yes	33.3	40.5	50.8	56.3	62.8	71.3	72.9	90.8	89.6	91.6	0.0154
No	9.3	7.3	6.4	5.0	5.2	6.4	13.7	19.7	23.7	27.2	(ref)
Medicaid Status											
Yes	16.7	21.2	26.3	32.1	39.4	47.2	52.1	65.9	65.5	69.7	<.0001
No	25.8	26.7	30.9	29.2	28.7	30.4	34.5	44.6	47.9	49.1	(ref)
Private Insurance											
Yes	18.4	21.6	27.4	29.5	29.3	29.8	25.1	30.2	28.8	24.9	<.0001
No	24.2	26.2	29.7	31.8	38.7	47.8	61.5	80.2	84.6	93.9	(ref)
Residential											
New York City	27.3	31.6	37.4	41.7	49.9	57.1	64.4	87.8	89.1	92.4	(ref)
Rest of the state	15.3	16.2	19.8	19.6	18.1	20.6	22.2	22.7	24.2	26.4	<.0001
Region (ROS)											
-Capital Area	3.1	2.6	4.0	2.0	1.8	2.6	2.3	1.7	1.6	1.7	(ref)
-Central Region	0.3	0.4	0.7	1.0	1.0	0.6	0.9	1.3	1.2	1.7	<.0001
-Metropolitan Area	10.3	11.0	13.0	14.2	13.1	15.2	16.0	17.5	19.7	20.3	<.0001
-Western Region	1.6	2.2	2.1	2.3	2.2	2.2	3.0	2.2	1.8	2.6	0.4967
Annual ASD prevalence	42.6	47.9	57.1	61.3	68.1	77.6	86.6	110.5	113.3	118.8	<.0001
Total no. of ASD	**1,317**	**1,410**	**1,735**	**2,087**	**2,269**	**2,443**	**2,587**	**3,027**	**3,169**	**3,458**	

Figure 2.2. Trend in ASD prevalence among eligible children in New York State Early Intervention Program, from 2005-2014, by gender

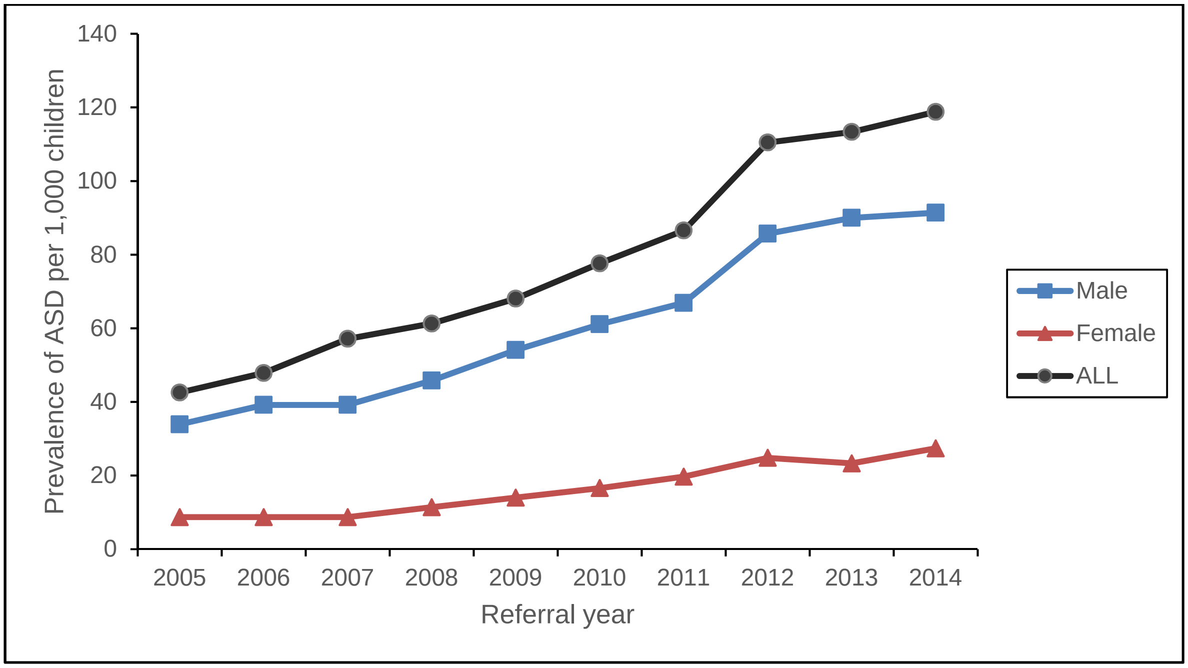

Figure 2.3. Trend in ASD prevalence among eligible children in New York State Early Intervention Program, from 2005-2014, by race/ ethnicity

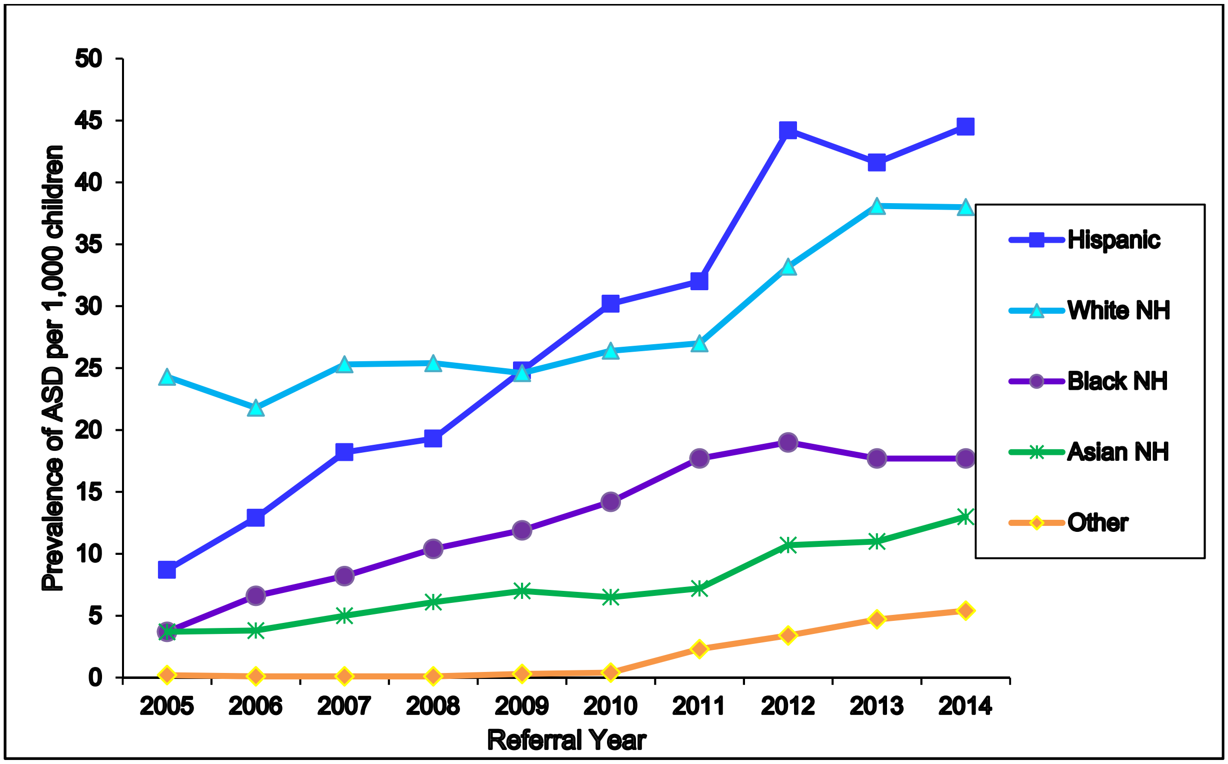

Figure 2.4. Trend in ASD prevalence among eligible children in New York State Early Intervention Program, from 2005-2014, by insurance status

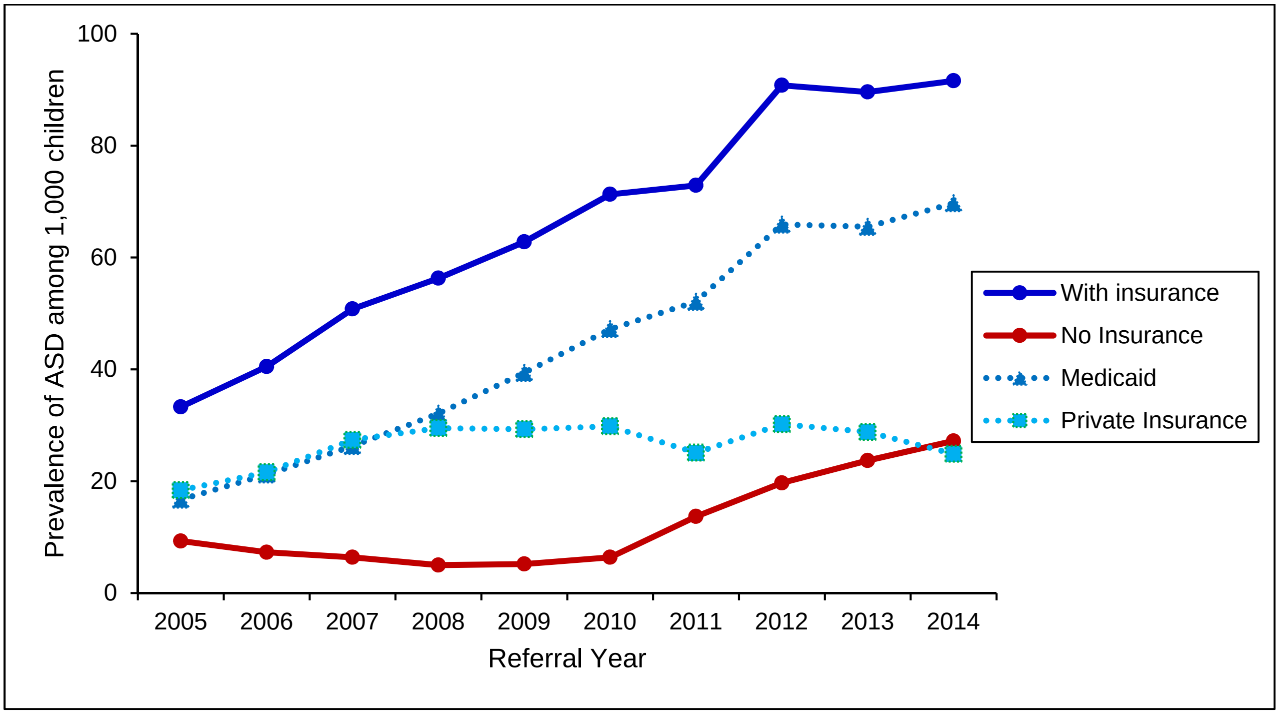

Figure 2.5. Trend in ASD prevalence among eligible children in New York State Early Intervention Program, from 2005-2014, by geographic location

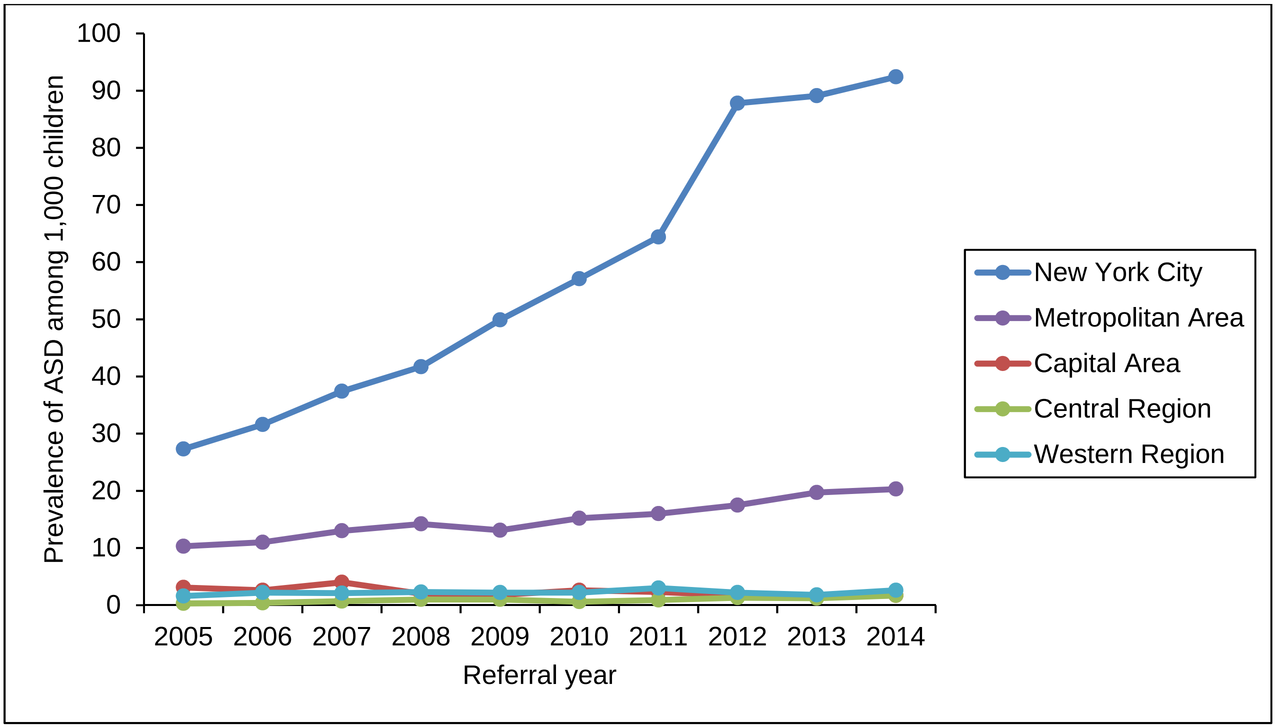

Table 2. 4. Prevalence autism spectrum disorder among 1,000 eligible children from **New York City**, in the New York State Early Intervention Program, by selected characteristics, 2005-2014.

Characteristics	**Total Eligible Children**	**Total No. with ASD**	**ASD Prevalence per 1,000 children (95% CI)**	**Prevalence Ratio (95% CI)**	***p-value***
Sex					
Male	104,586	13,601	130.1 128.0 – 132.1)	2.0 (1.9 – 2.1)	<.0001
Female	57,369	3,697	64.4 (62.4 – 66.5)	(ref.)	
Race					
Hispanic	50,576	6,693	132.3 (129.4 – 135.3)	1.7 (1.6 – 1.7)	<.0001
American Indian	220	27	122.7 (79.4 – 166.1)	1.6 (1.1 – 2.2)	0.0138
Asian NH	11,946	1,830	153.2 (146.7 – 159.5)	1.9 (1.8 - 2.1)	<.0001
Black NH	23,500	3,127	133.1 (128.7 – 137.4)	1.7 (1.6 - 1.8)	<.0001
White NH	50,596	3,976	78.6 (76.3 – 81.0)	(ref.)	
Other	1,604	317	197.6 (178.1 – 217.1)	2.5 (2.3 - 2.8)	<.0001
Insurance status					
Yes	142,001	15,135	106.6 (105.0 – 108.2)	1.0 (0.9 – 1.0)	0.6729
No	20,174	2,170	107.6 (103.3 – 111.8)	(ref.)	
Medicaid Status					
Yes	105,108	11,114	105.7 (103.9 – 107.6)	0.9 (0.9 – 1.0)	0.0868
No	57,076	6,191	108.5 (105.9 – 111.0)	(ref.)	
Private					
Yes	44,357	5,036	113.5 (110.6 – 116.5)	1.1 (1.0 – 1.1)	<.0001
No	117,818	12,269	104.1 (102.4 – 105.9)	(ref.)	

Table 2. 5. Prevalence autism spectrum disorder among 1,000 eligible children from **Rest of the State**, in the New York State Early Intervention Program, by selected characteristics, 2005-2014

Characteristics	**Total Eligible Children**	**Total No. with ASD**	**ASD Prevalence per 1,000 children (95% CI)**	**Prevalence Ratio (95% CI)**	***p-value***
Sex					
Male	94,235	4,895	51.2 (50.5 – 53.4)	1.9 (1.8 – 2.0)	<.0001
Female	47,545	1,300	27.3 (25.9 – 28.8)	(ref.)	
Race					
Hispanic	23,380	1,179	50.4 (47.6 – 53.2)	1.2 (1.2 – 1.3)	<.0001
American Indian	243	7	28.8 (7.8 – 49.8)	0.7 (0.3 – 1.7)	0.3466
Asian NH	3,794	256	67.5 (59.5 – 75.5)	1.6 (1.5 – 1.9)	<.0001
Black NH	11,339	503	44.4 (40.6 – 48.2)	1.1 (1.0 – 1.2)	0.0809
White NH	95,638	3,913	40.9 (39.7 – 42.2)	(ref.)	
Other	3,152	164	52.0 (44.3 – 59.8)	1.3 (1.1 – 1.5)	0.0020
Insurance status					
Yes	115,497	4,724	40.9 (39.8 – 42.0)	0.7 (0.7 – 0.8)	<.0001
No	26,313	1,473	56.0 (53.2 – 58.8)	(ref.)	
Medicaid Status					
Yes	60,561	1,938	32.0 (30.6 – 33.4)	0.6 (0.5 – 0.6)	<.0001
No	81,249	4,259	52.4 (50.9 – 54.0)	(ref.)	
Private					
Yes	62,376	3,031	48.6 (47.0 – 50.3)	1.2 (1.2 – 1.3)	<.0001
No	79,434	3,166	39.9 (38.5 – 41.2)	(ref.)	

Figure 2.6. Trend in ASD prevalence among eligible children in New York State Early Intervention Program, from 2005-2014, stratified by residential location and gender

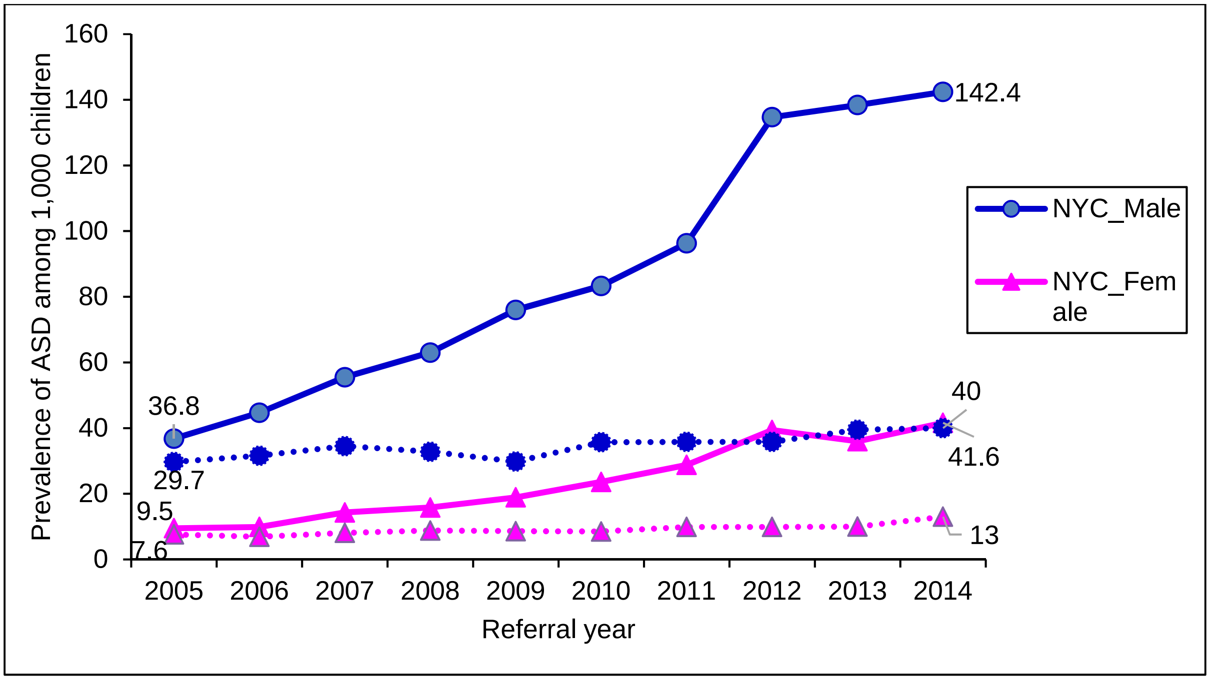

Figure 2.7. Trend in ASD prevalence among eligible children in New York State Early Intervention Program, from 2005-2014, stratified by residential location and insurance status

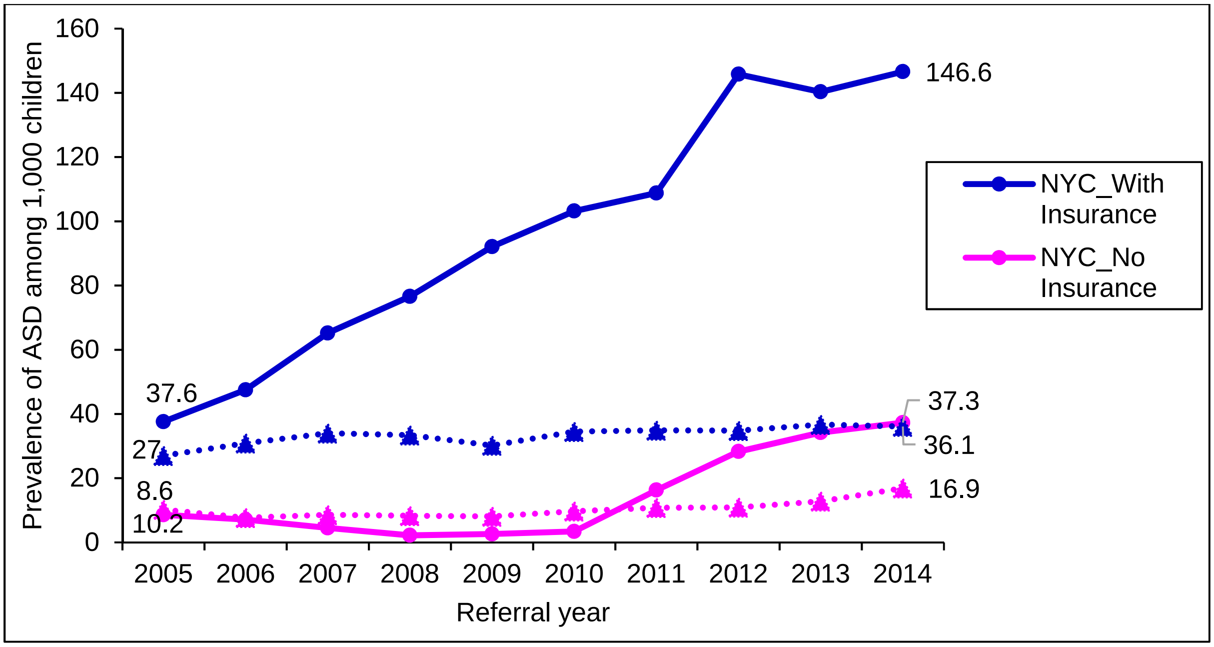

Figure 2.8. Trend in ASD prevalence among eligible children from **New York City**, in the New York State Early Intervention Program, from 2005-2014, by race

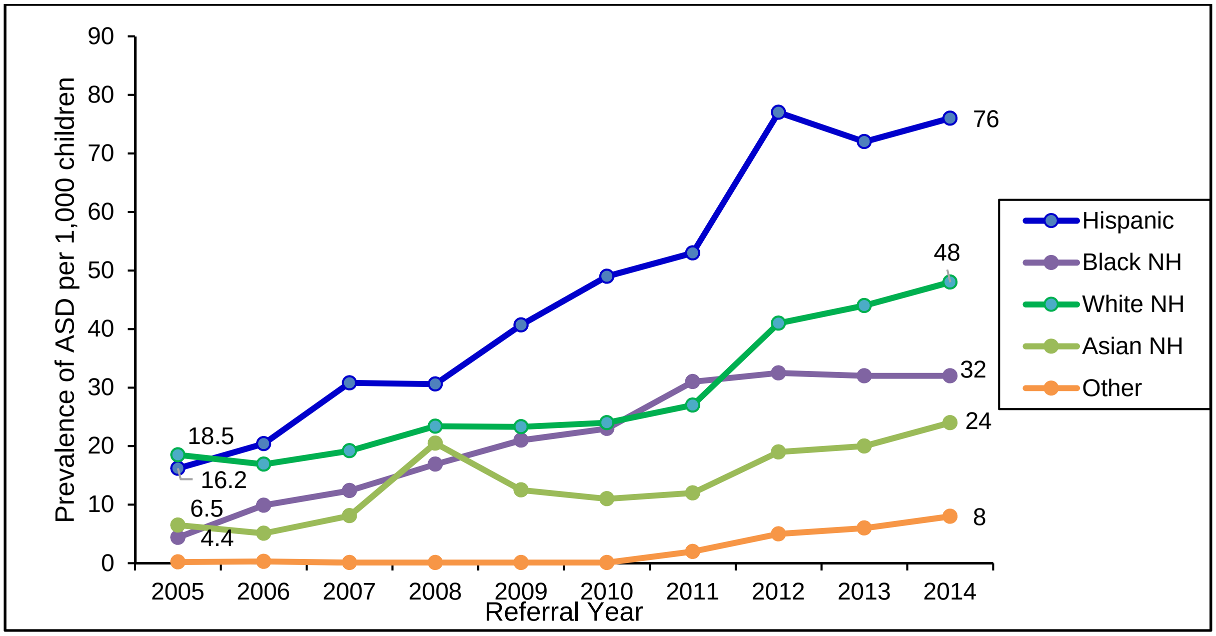

Figure 2.9. Trend in ASD prevalence among eligible children from **Rest of the State**, in the New York State Early Intervention Program, from 2005-2014, by race

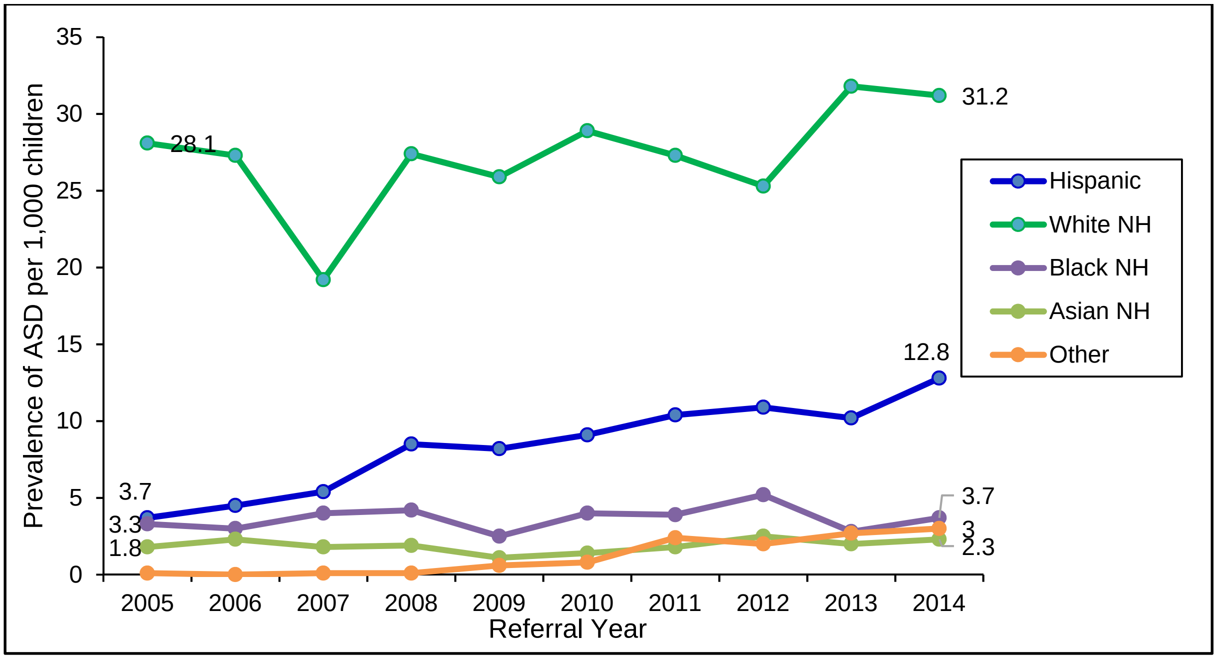

Table 2.6. Comparison of selected characteristics between children with ASD and without ASD who were eligible in NYSEIP, 2005-2014

Characteristics	**ASD**		**Non-ASD**		**p-value***
	n	**%**	**n**	**%**	
Gender					<.0001
Male	18,496	78.73%	180,329	64.35%	
Female	4,997	21.27%	99,917	35.65%	
Total	23,493	100%	280,246	100%	
Race/ ethnicity					<.0001
Hispanic	7872	35.79%	66,085	26.02%	
American Indian	34	0.15%	429	0.17%	
Asian NH	2086	9.48%	13,654	5.38%	
Black NH	3630	16.50%	31,210	12.29%	
White NH	7891	35.88%	138,345	54.47%	
Other	481	2.19%	4,275	1.68%	
Total	21,994	100%	253,998	100%	
Insurance status					0.3552
Yes	19,859	84.50%	237,643	84.73%	
No	3,643	15.50%	42,844	15.27%	
Total	23,502	100%	280,487	100%	
<u>*Medicaid*</u>					0.0009
Yes	13,052	44.46%	152,619	54.41%	
No	10,450	55.54%	127,868	45.59%	
Total	23,502	100%	280,487	100%	
<u>*Private insurance*</u>					0.0085
Yes	8,067	34.32%	98,668	35.18%	
No	15,435	65.68%	181,819	64.82%	
Total	23,502	100%	280,487	100%	
Residency					<.0001
New York City	17,305	73.63%	144,870	51.65%	
Rest of the state	6,197	26.37%	135,613	48.35%	
Total	23,502	100%	280,483	100%	

Missing values were excluded from the tables and from chi-square calculations
** p-value by chi-square test of the difference in distribution for each independent variable between children with and without ASD.*

Table 2.7. Comparison of functional areas and developmental delay scores between children with ASD and without ASD who were found eligible in NYSEIP, 2005-2014

Functional Areas	**ASD**		**Non ASD**		**p-value**
	n	**%**	**n**	**%**	
Adaptive					0. 1194
0	11841	56.42%	3274	56.94%	
0.5	5040	24.01%	1310	22.78%	
1	4107	19.57%	1166	20.28%	
Total	20988	**100%**	5750	**100%**	
Cognitive					0.1768
0	3217	15.33%	912	15.85%	
0.5	4877	23.23%	1273	22.13%	
1	12896	61.44%	3568	62.02%	
Total	20990	**100%**	5753	**100%**	
Communication					0.0884
0	1686	8.02%	480	8.34%	
0.5	1652	7.86%	499	8.67%	
1	17674	84.11%	4779	83.00%	
Total	21012	**100%**	5758	**100%**	
Social emotional					0.0210
0	1759	8.37%	417	7.24%	
0.5	2786	13.26%	777	13.49%	
1	16473	78.38%	4565	79.27%	
Total	21018	**100%**	5759	**100%**	
Physical					0.7417
0	3848	18.31%	1067	18.52%	
0.5	4272	20.32%	1145	19.88%	
1	12900	61.37%	3548	61.60%	
Total	21020	**100%**	5760	**100%**	
Developmental delay					<.0001
Mean	3.49		1.78		
Median	1.5		1.5		
Standard deviation	0.98		1.09		
Ranges	0-5		0-5		

Table 2.8. Comparison of selected characteristics between children with ASD or without ASD who enrolled in NYSEIP by region, 2005-2014.

Characteristics	**NYC**			**ROS**		
	With ASD, %	**Without ASD, %**	**p-value**	**With ASD, %**	**Without ASD, %**	**p-value**
Gender			<.0001			<.0001
Male	78.6	62.9		79.0	65.9	
Female	21.4	37.1		21.0	34.1	
Race/ ethnicity			<.0001			<.0001
Hispanic	41.9	35.8		19.6	16.9	
American Indian	0.2	0.2		0.1	0.2	
Asian NH	11.5	8.3		4.3	2.7	
Black NH	19.6	16.6		8.4	8.2	
White NH	24.9	38.1		65.0	69.7	
Other	2.0	1.1		2.7	2.3	
Insurance status			0.6730			<.0001
Yes	87.5	87.6		76.2	81.7	
No	12.5	12.4		23.8	18.3	
<u>Medicaid</u>			0.0870			<.0001
Yes	64.2	64.9		31.3	43.2	
No	35.8	35.1		56.8	68.7	
<u>Private insurance</u>			<.0001			<.0001
Yes	29.1	27.1		48.9	43.8	
No	70.9	72.9		51.1	56.2	

CHAPTER 3.

AGE AT AND TIME TO DIAGNOSIS OF AUTISM SPECTRUM DISORDER AMONG ELIGIBLE CHILDREN IN THE NEW YORK STATE EARLY INTERVENTION PROGRAM

3.1. Abstract

Background: An early diagnosis may lead to early, more intensive intervention and better outcomes for children with an autism spectrum disorder (ASD). This study examined age at ASD diagnosis by children's sociodemographic characteristics and timing of ASD diagnosis and receipt of related-services among eligible children in the New York State Early Intervention Program (NYSEIP) and assessed trends on the timing of early intervention services from 2005 to 2014.

Methods: Data from the New York State Early Intervention data systems were evaluated for children with an ASD diagnosis. Age at ASD diagnosis was calculated as the difference between the date of the ASD diagnosis and the child's date of birth. Age of referral to the NYSEIP was calculated as the difference between the date of a child referred to the program and the child's date of birth. Time to evaluation was calculated as the length of time between referral date and first evaluation date in the NYSEIP. Time to ASD diagnosis was the length of time between referral date and the date when ASD diagnosis was made. Parametric statistics tests; t-test, one-way analysis of variance (ANOVA) and Tukey's honest significant difference post hoc test, were conducted to compare means between subgroups of children's characteristics (gender, race/ethnicity, insurance status and geographic locations). Trends were examined using linear regression analysis.

Results: The mean age at ASD diagnosis was 25.78 months, ranging from 1 – 36 months. About 99.67% children had their ASD diagnosis between 13-36 months-old. The mean age at ASD diagnosis and age of referral were similar across gender, race and insurance status. The average time to receive ASD diagnosis from referral was 4.97 months or 21.59 weeks (SD=5.67 months or 24.60 weeks) and varied across geographical region, race and ASD subtype. Children residing

in Western and Central Region were diagnosed with ASD at an older age than children from other parts of New York State and had a longer time to receipt the diagnosis after referral in the NYSEIP (mean= 38.84 and 32.58 weeks, respectively). Compared to children from other races, white non-Hispanic children had a longer period of time between referral and receiving an ASD diagnosis. Trend analyses demonstrate that timing of services for ASD children in NYSEIP remained stable from 2005 to 2014.

Conclusion: This study indicated that there were some discrepancies in age at ASD diagnosis and time to receive ASD diagnosis by race and geographical location. The results from this analysis can support the evaluation of the NYSEIP and can inform local early intervention providers and healthcare professionals about the experience of evaluating children with ASD in the NYSEIP.

3.2. Background

An early diagnosis for autism spectrum disorder (ASD) is crucial for having early intervention.[1–3] ASD, a neurodevelopmental disorder characterized by impairment in social and communication and repetitive behaviors, is a public health concern because of the tremendous increase in prevalence and unknown etiology.[4–7] Diagnosis of ASD is difficult and no medication treatment has been proven effective to eliminate core symptoms. The only evidence-based treatment for ASD is intensive behavior intervention that begins early. Early intervention provides an optimal opportunity to take advantage of brain plasticity, which allow for significant improvement of cognitive, language abilities and adaptive behaviors in children with ASD upon receiving intervention.[8,9]

Research demonstrates that intensive early intervention following early identification can improve quality of life and functioning in a range of areas for young children with ASD.[10–16] Late recognition of symptoms has been associated with worse outcomes in social and communication functioning and poorer nonverbal cognitive skills. [21–25] Parents and/or pediatricians often are able to identify children earlier. Results of a recent review of the literatures indicate that the use of routine screenings result in increased referrals.[23–32] The American Academy of Pediatrics (AAP) Committee on Children with Disabilities released a policy report that charges all pediatricians to engage in both ongoing surveillance of young children and autism-specific screenings at 18 and 24 months of age.[30,33,34] However, some major barriers to systematic early identification still exist. These barriers includes lack of physician familiarity with screening measures, lack of time and resources and failure to follow-up after a positive screening outcome.[36–38] These factors may contribute to the regional variation in age at ASD diagnosis suggesting that local policies and resources may influence age at ASD diagnosis.[38–47]

Gaining better functioning for an ASD child through early intervention may also translate into reduced family and community financial burdens as excess costs for educational placements and family or caregiver stress in taking care of the affected child can be decreased.[47–56] In the United States, the total costs per year for children with ASD were estimated to be between $11.5 - $60.9 billion, representing a variety of direct and indirect costs, from medical care to special education to lost parental productivity.[56–58] On average, medical expenditures and behavioral interventions for children and adolescents with ASD were 4.1–6.2 times greater than for those without ASD. [60–62] Because early intervention has been proven to increase levels of functioning and improve positive behavior, early access to effective early intervention services may eventually result in less restrictive educational environments and reduced expenses over the lifetime of the child with ASD.

Although research suggests that ASD can be reliably diagnosed as early as 18 months of age, many studies have found that a significant proportion of children are not diagnosed until school age.[63–67] Recent studies from across the United States, United Kingdom, Europe, Canada, Australia and Asia show that the average age of ASD diagnosis was delayed until after 3 years and ranged from 38 to 120 months.[67–75] Fortunately, given the increased awareness of autism, age of initial diagnosis has generally decreased over time. The Center for Disease Control and Prevention (CDC) through Autism and Developmental Disabilities Monitoring (ADDM) Network found that in the 2002 study, the mean age at first diagnosis was 5.7 years while in 2006 was 4.4 years.[70] The mean age of receiving initial ASD services from California Department of Developmental Services decreased from 6.9 to 3.3 years from 1987 to 1994.[77]

A diagnosis of ASD is not required for children to be found eligible for the Early

Intervention Program (EIP). A child may be found eligible as a result of delays in five developmental areas: adaptive, cognitive, communication, physical or social emotional. A child may receive the ASD diagnosis in the EIP. In the United States, the Individuals with Disabilities Education Act (IDEA) Part C supports state's EIPs with formula grants.[78,79] Participation in the EIP is voluntarily; all states and territories participate. Under the EIP, states are responsible for ensuring that appropriate early intervention services are made available to all eligible children from birth up to age three with disabilities and their families. At age three, eligible children transition to school-based special education services.

The New York State Early Intervention Program (NYSEIP), which has been operating since July 1, 1993, is part of the national EIP for infants and toddlers with disabilities and their families.[80,81] In the NYSEIP, the local program in the county receives referrals from parents and other professionals who have identified a child suspected of delay or diagnose with a condition (such as Down's syndrome) with a high probability of delay. After referral, a child is evaluated to determine his/her eligibility for the EIP (Figure 1.1). Children may be referred with or without definitive diagnosis of ASD or other developmental delays. All children referred to the NYSEIP are entitled to a multidisciplinary evaluation to determine areas of delays and to identify appropriate services to achieve desired outcomes. As part of a child's initial or subsequent evaluations, a diagnosis of ASD may be obtained.

Studies have identified that a child's age at ASD diagnosis varies by ASD subtypes, race/ethnicity, children's characteristics, the clinical presentation, parental and physician behaviors and local/ state policies.[27,40,82–93] Previous studies revealed that diagnosis age varies by subtype with notably higher diagnosis ages for Asperger's disorder than autistic disorder and that a later ASD diagnostic age was associated with non-Hispanic black and Hispanic race/ ethnicity, low income and lack of awareness among healthcare professionals and parents. Some of these factors along with factors that influence early screening of ASD are considered modifiable or can be targeted for earlier detection.

Beyond general studies of predictive factors, there have been few studies of age at ASD diagnosis in an early intervention program setting. Most studies evaluated general populations and were limited by small sample size and a short study period (i.e. cross-sectional method). There have been no known studies evaluating age of referral for children who are subsequently diagnosed with ASD in an EIP. Another aspect that needs to be studied is the waiting time for children in EIP to be evaluated and diagnosed with ASD. This study examined age at ASD diagnosis among eligible children in the NYSEIP by children's characteristics. This study examined the age of referral, time of evaluation and time of ASD diagnosis among those children. Trends were assessed related to timing of ASD diagnosis among children who receiving services from 2005 to 2014. This information can inform about the timing of ASD diagnosis for children by specific demographic characteristics who have been served by the NYSEIP.

3.3 Methods

Data source

The data were obtained from the information systems for the administration of the Early Intervention Program in New York State Department of Health. The system is comprised of two databases: New York Early Intervention System (NYEIS) and Kids Integrated Data System (KIDS). NYEIS is a centralized, web-based, state-of-the-art system that electronically manages the NYSEIP administrative tasks and provides for information exchanges. This system is designed to support NYSEIP's service delivery, financial, administration, and management activities at both the local and state levels. These activities include initial intake, evaluation, eligibility determination, Individualized Family Service Plan development, service provision, and all financial aspects including insurance, claiming, payments, and Medicaid reimbursement. Starting in 2010, KIDS was being replaced by NYEIS.

The study protocol was approved by the Institutional Review Board at the State University of New York at Albany and the New York State Department of Health.

Study Population

A total of 20,637 children diagnosed with autism spectrum disorder (age 0-36 months) who enrolled in the New York State Early Intervention Program (NYSEIP) and recorded in the databases from January 1, 2005 to December 31, 2014 were included in the analysis. These children received their ASD diagnosis in the NYSEIP and represented 6.8 % of total eligible children (303,389) during this study period. Children with ASD were defined by International Classification of Diseases (ICD) versions 9 and 10. The ICD 9 code was used for diagnoses before October 2015 which included autistic disorder (code 299.0) including infantile autism (299.00), Asperger's disorder (code 299.80), and pervasive developmental disorder and not otherwise specified or PDD-NOS (code 299.90). The ICD 10, which was used for diagnoses made in October 2015 and after, includes autistic disorder and infantile autism (code F84.0), Asperger's syndrome (code F84.5), other pervasive developmental disorders (code F84.8) and pervasive developmental disorder, unspecified and atypical autism (code F84.9).

Data Analysis

Demographic variables pertaining to children in the study were extracted from the New York State Early Intervention data systems (NYEIS and KIDS). These included date of birth, sex, race/ ethnicity, Medicaid status, private insurance status and geographic locations. Missing data were less than 5% in each referral year and were categorized as missing completely at random (MCAR).

Age at ASD diagnosis was calculated by subtracting date of birth from date of ASD diagnosis recorded in the database. Age of referral was obtained by subtracting date of birth from date of referral to the NYSEIP. Timing of early intervention services received included time of evaluation, which is the length of time between referral time and evaluation time, and time of ASD diagnosis, which is the length of time between referral time and establishment of ASD diagnosis. Diagnoses were recorded in the database and were not verified by medical record review.

Variables were described using frequencies and proportions or with means and ranges, as appropriate. The mean age at ASD diagnosis, median, associated range, standard deviation and confidence interval were calculated for all levels of each categorical variable. The similar measures also applied for age of referral, time of evaluation and time of ASD diagnosis. The Kolmogorov-Smirnov Test of normality were employed for each variable which resulted in using parametric statistics tests (t-test and one-way ANOVA) to compare means between subgroups of children's characteristics. An overall statistically significant difference in groups by one-way ANOVA were further tested using Tukey's honestly significant difference (HSD) test to confirm differences between subgroups specifically. Statistical data analyses were performed using SAS program 9.4.

To further characterize and analyze the trends of the timings of ASD diagnosis in the NYSEIP, linear regression analysis was performed. Plots and statistical analysis for trends were performed using Analysis ToolPak by Microsoft Excel 2016.

3.4. Results

Age at ASD diagnosis

The mean age at ASD diagnosis for children in the NYSEIP was 25.78 months (SD=4.78), ranging from 1 – 36 months (Table 3.1). About 99.67% ASD children who were eligible for the NYSEIP had their ASD diagnosis between 13 months-old and 36 months-old (Table 3.2). About 38.11%, or 7,864 children, received their ASD diagnosis between ages 1 and 2 years and 61.55 % children were diagnosed between ages 2 and 3 years. Less than 1% had an ASD diagnosis before their first year of age. Regarding children's characteristics, boys were statistically significantly older in age at ASD diagnosis than girls (25.81 months vs 25.68 months, p=<.0001) (Table 3.3). Children who were insured with private insurance (M=25.49 months) were diagnosed younger than children without private insurance (M=25.94 months).

Results of a one-way ANOVA indicated differences in age at ASD diagnosis by races in the NYSEIP (p=<.0001). Tukey's post hoc comparisons of the groups indicated that the mean age at ASD diagnosis for white non-Hispanic (NH) children (M=25.48 months) was younger than black NH (M=26.10 months), Asian NH (M=26.42 months) and other races NH (M=26.26 months).

Children residing in New York City (M=25.62 months) were significantly younger with ASD diagnosis than children from the Rest of the State (ROS) (M=26.17 months). In addition, a one-way ANOVA indicated differences in age at ASD diagnosis among the four regions in ROS (p=<.0001). Tukey's post hoc comparisons of the groups indicated that the mean age at ASD diagnosis for children from Western Region (M=29.10 months or 2 years 5 months) was significantly older than children from the Central Region (M=27.41 months) and Capital Area Region (M=26.71 months) and Metropolitan Region (25.58 months).

Age of referral

The mean age of referral for children diagnosed later with ASD in the NYSEIP was 21.08 months (Table 3.1). There were differences in age of referral by: gender, race, Medicaid status, private insurance status and geographic locations (Table 3.4). The differences in age of referral among ASD children were considered not clinically meaningful, which was around 1 to 2 months.

The average age of referral for boys (M=21.19 months) was significantly older than girls (M=20.67 months). Children with Medicaid (M=20.89) were more likely to have been referred earlier to NYSEIP than children without Medicaid (M=21.31). There was a statistically significant difference of the average age of referral for children with autism by their geographic locations, however, the average age of referral for children from NYC was not meaningfully different from the Rest of the State (M=21.02 and M=21.23, respectively). Results of a one-way ANOVA indicated differences in the mean age of referral among children's races in the NYSEIP (p=<.0001). Tukey's post hoc comparisons of the groups indicated that the mean age of referral for white non-Hispanic (NH) children (M=20.28 months) was significantly earlier than black NH (M=21.56 months), Asian NH (M=22.29 months) and Hispanic (M=21.08 months).

Time to evaluation

The mean length of time between referral date and evaluation date for children with ASD in NYSEIP was 1.02 months (4 weeks) and there was no difference between boys and girls (Table 3.5). Results of a one-way ANOVA indicated differences in the average time of evaluation among children's races in the NYSEIP (p=<.0001). Tukey's post hoc comparisons of the groups indicated that the mean evaluation time for white non-Hispanic (NH) children (M=3.98 weeks, SD=4.25) was significantly earlier than all other races and Hispanic children. The time from referral to evaluation was slightly different between children in New York City and Rest of the State (M=4.49 weeks and 4.21 weeks). There were no meaningful differences between regions. Most children were evaluated in 4-5 weeks from referral to have their evaluation.

Time to ASD diagnosis

The mean time from referral to ASD diagnosis for children in the NYSEIP was 4.97 months or 21.59 weeks (Table 3.1). There were significant differences in time of ASD diagnosis by children's characteristics (Table 3.6). Boys (M=21.32 weeks, SD=24.20) were diagnosed sooner than girls (M=22.58 weeks, SD=26.02). The mean time to ASD diagnosis for white NH children (M=24.01 weeks, SD=25.60) was significantly later compared to other races, F (5, 19121) = 19.12, p=<.0001. There were differences between mean times for diagnosis ASD in Asian NH and white NH (5.3 weeks), between Hispanic and white NH (3 weeks) and between black NH and white NH (3.1 weeks). In addition, there were differences by geographic locations for NYS and ROS where children from ROS (M=23.46 weeks, SD=23.33) had longer time to ASD diagnosis from referral compared to children from NYC (M=20.85 weeks, SD=25.04).

There were differences in the average time of ASD diagnosis among the four regions in ROS (p=<.0001). Children from the Western Region had the longest average time from referral to ASD diagnosis (38.84 weeks).

Trends in age at ASD diagnosis, age of referral, time to evaluation and time to ASD diagnosis

No trend was indicated (p=0.4239) for annual average age at ASD diagnosis between 2005 and 2014 (Figure 3.1). Similarly, no trend was observed in age of referral for children with ASD in NYSEIP within this period of study (p=0.8642). The age of referral ranged from 20.49 months to 21.86 months in 2014. The length of time between referral date to evaluation date and the average time to evaluation was consistent from 2005 to 2014 (Figure 3.2). The average time to ASD diagnosis from referral was consistent (p=0.7609) (Figure 3.3).

3.5. Discussion

This study revealed that the average age at diagnosis of ASD in children 0 – 36 months enrolled in New York State Early Intervention Program was 25.79 months, with the most children receiving a diagnosis between ages two and three years. These findings support that ASD diagnosis can be made at younger age.[63,67,94] Almost all ASD diagnoses (99%) were made between ages one and three years. While there were diagnoses of ASD reported before age one, the dates and diagnoses were not confirmed. Since this study was of children in the NYSEIP, the age at ASD diagnosis in this study is younger than the nationally reported average age at ASD diagnosis of four years old.[70,95,96]

Results further indicate that there were statistical differences in age at ASD diagnosis by children's sociodemographic characteristics, although differences were not necessarily meaningfully different. The patterns of race-ethnicity findings are similar to previous studies where non-Hispanic white children received their ASD diagnosis at a younger age than children with other race/ ethnicities. Non-Hispanic white children were also referred earlier to the program compared to non-Hispanic black, non-Hispanic Asian and Hispanic children. Research suggests that early identification of ASD leads to early diagnosis and greater likelihood of receiving intensive and early intervention. Most studies have identified a discrepancy in both time to evaluation and to diagnosis of ASD children by ethnicity.[82,88,97,98] In the NYSEIP, referral is followed by evaluation, at which point an ASD diagnosis can be made, to establish the eligibility. This study found that even though non-Hispanic white children were younger at referral and evaluation, the time to their ASD diagnosis in the program was significantly longer than children of other races.

This study also demonstrated that there were geographic differences in age at ASD diagnosis, age of referral, time to evaluation and time to ASD diagnosis for children who received services in the NYSEIP. Children from NYC received their ASD diagnosis at a younger age than children from the ROS. In the Western and Central Regions, children were older at the time of age at ASD diagnosis (2 years, 5 months and 2 years, 3 months) and significant differences of four to five months were observed in the time to receive the diagnosis after referral to the NYSEIP compared to children from New York City or Metropolitan Area. The delay of four to five months may be clinically meaningful given that neural plasticity declines after three years of age.[8,9,99] Moreover, research has confirmed that better outcomes result from longer duration and greater intensity of treatment.[11,100–102] Practical intervention guidelines for children with ASD recommend a minimum of 25 hours per week of comprehensive service. Therefore, about 400-500 hours in intensive behavioral intervention may be lost with four to five month delay.

As stated in other studies, geographic locations are associated with close proximity to health care providers (such as neurologists, psychiatrists and psychologists) and the growing awareness in the urban community of ASD.[42,103–105] Children from the Western Region of New York State which may be categorized as more rural than other regions have been shown to receive ASD diagnosis later than children from more urban settings such as NYC, Capital Area Region and Metropolitan Region. These results support findings from previous studies regarding the relationship between urbanicity and the growing recognition of the importance of place in predicting health and health care in general.[106,107] NYC and its surrounding (the Metropolitan Region) and the Capital Area Region have more ASD specialists and providers. In addition, these areas are the most densely populated areas with more children with ASD; therefore, awareness about ASD may be greater than in other areas or regions of the state. Local differences in age at diagnosis have been reported in studies from different countries (the United Kingdom, Australia and Canada) suggesting that characteristics of local health care systems play a role in determining diagnostic timing.[40,69,108]

The study found that age at ASD diagnosis was not different between children regarding their insurance status, both Medicaid and private insurance. Although there are statistically significant differences between these subgroups in terms of age of referral, time of ASD diagnosis and time of evaluation, the differences were small and not meaningfully different. Medicaid status is commonly used for socioeconomic level prediction as a proxy of income but since services in the NYSEIP are delivered at no cost to the families, this variable may not be useful as an income proxy. New York State system of payments for the Early Intervention

Program includes the use of public insurance (such as Medicaid and Child Health Plus) and private insurance for reimbursement of early intervention services. Regardless of the insurance status, all eligible children are entitled to receive services. Therefore, Medicaid and private insurance status may not be useful to predict income differences in the NYSEIP. This study indicated that difference in age and time to ASD diagnosis for children was not clinically meaningful by insurance status.

The age at ASD diagnosis and other key timings of the NYSEIP services were not found to be significant in different by year in the 10-year period of study. Trend analyses demonstrated that age at ASD diagnosis for children in NYSEIP remained similar from 2005 to 2014. Given the age range of children in NYSEIP between 0 – 36 months, an ASD diagnosis obtained while in the program would be considered an early diagnosis, given that the average age at ASD diagnosis is four years old. This study supports that ASD can be detected early in life. Therefore, efforts should continue to identify children with ASD early so that they may experience early and intensive intervention for better outcomes in later life. There may be a need to focus educational efforts on primary care physician's, local pediatrician' or local other healthcare professional's ability in specific areas of the state such as the Western New York. The results of this study can inform policy makers at the state level about where to focus efforts on educating local physicians, early intervention providers, and families about the importance of early identification of ASD.

This study has several key strengths. First, it was the first study to examine timing of ASD diagnosis that focused on young children (0-36 months) and the study population large (n=20,637). Most other studies evaluated an older study population. The results of this study are also the first to be reported from New York State, which is not represented in national ASD surveillance study by CDC. Additionally, this project utilized a previously validated data source for all subjects, from a state-of-the-art system that electronically manages the NYSEIP. The use of administrative data eliminated the possibility of recall biases. A consistent data source throughout the study ensured the uniformity in data collection methods.[109–112]

This study's findings on geographical location differences in time to receive ASD diagnosis after referral suggest at least three things. First, trainings may be beneficial for local early intervention providers and service coordinators. Second, health and medical professionals may benefit from training about importance of screening and following up on ASD symptoms in the young children under three years old. The 'wait and see' attitude reported by some health professionals has been links to delays in ASD diagnosis.[113,114] Third, local capacity to serve children with ASD should be evaluated.

There are some important limitations of this study that warrant consideration. First, information on parental characteristics, co-occurring conditions and the severity of the condition were not included in the analysis. These factors have been identified as predictors of age at ASD diagnosis in all previous studies. The absence of these factors could limit the generalizability of the information. In particular, existence of comorbidities may have biased the age of ASD diagnosis in either direction. Children with more severe cognitive or social emotional delays may be more likely to be referred for an ASD evaluation; while other more subtle symptomology may lead to a delay in the ASD evaluation. Another limitation of the study was that the professionals performing the evaluations and the types of the evaluations tools used to establish the ASD diagnoisis were not included. The information was available in NYEIS but not KIDS. Future studies should evaluate these factors.

3.6. Conclusion

The mean age of ASD diagnosis for children in New York State Early Intervention Program (NYSEIP) was 25.79 months (about 2 years, 1 month). This study indicated that there were some discrepancies in age at ASD diagnosis by children’s sociodemographic characteristics. White non-Hispanic children received their ASD diagnosis at a younger age than children with other race-ethnicity backgrounds. This study also demonstrated that there were geographic differences in the age at ASD diagnosis and the period of time between referral to obtain ASD diagnosis among eligible children in the NYSEIP. Delays in receiving an ASD diagnosis were evident between regions which may result in delays accessing early intervention and family support system. The age at ASD diagnosis for children in NYSEIP remained constant from 2005 to 2014. Conducting time-trend analysis in autism-related services as a form of longitudinal ecological study may provide a dynamic view of the NYSEIP population. The result of this analysis can inform policy makers about the need for targeted outreach and education of local early intervention providers and healthcare professionals to ensure timely diagnosis of ASD.

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3.7. Appendix

Table 3. 1. Average age at diagnosis, age of referral and times of several early intervention services for children with autism spectrum disorder in New York State Early Intervention Program, 2005-2014.

Timing of EI services (months)	Mean	Median	Standard Deviation	Ranges
Age at ASD diagnosis	25.78	26	4.78	1 - 36
Age of referral	21.08	22	6.46	0 - 36
Time to evaluation	1.02	1.0	1.18	0 - 25
Time to ASD diagnosis	4.97	2.0	5.67	0 - 35

Table 3. 2. Frequency of diagnoses and proportion of children in New York State Early Intervention Program diagnosed with autism spectrum disorder by age group.

Age group	No. of children diagnosed	Percentage	(95% CI)
<= 6 months	16	0.07 %	(0.04 % - 0.12 %)
7 – 12 months	54	0.26 %	(0.19 % - 0.33 %)
13 – 24 months	7,864	38.11 %	(37.44% - 38.77 %)
25 – 36 months	12,703	61.55 %	(60.89 % - 62.22 %)

Figure 3. 1. Distribution age at ASD diagnosis for children in the New York State Early Intervention Program

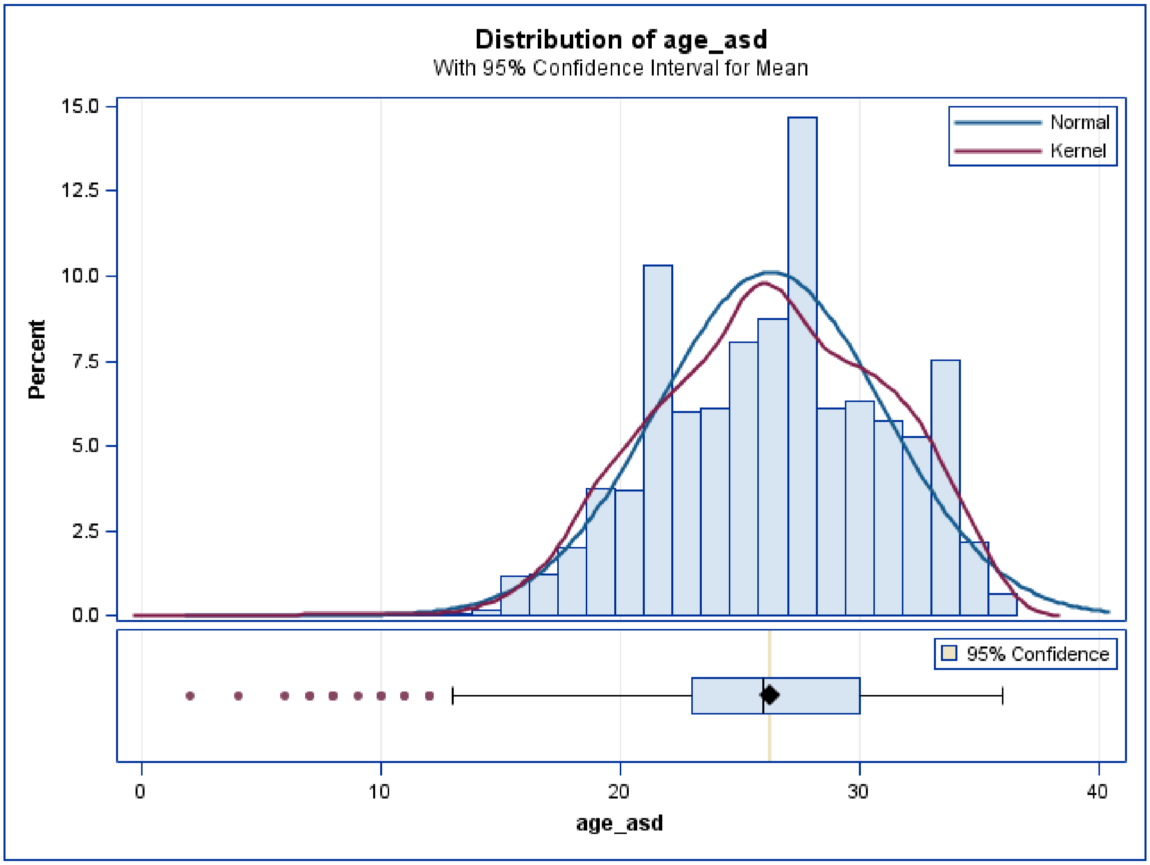


Table 3. 3. Age at ASD diagnosis for children in New York State Early Intervention Program, by characteristics

Characteristics	N	Age at ASD Diagnosis (months)			
		Mean	SD**	95% CI	*p-value*
Gender					<.0001*
Male	16,233	25.81	4.77	25.74 - 25.88	
Female	4,397	25.68	4.83	25.53 - 25.82	
Race					<.0001***
Hispanic	6,840	25.70	4.74	25.59 - 25.81	
American Indian	31	27.45	0.82	25.78 - 29.13	
Asian NH	1,700	26.42	4.44	26.21 - 26.63	
Black NH	3,141	26.10	4.62	25.94 - 26.27	
White NH	7,137	25.48	4.97	25.36 - 25.59	
Other NH	396	26.26	4.55	25.80 - 26.70	
Medicaid					<.2704
Yes	11,307	25.81	4.73	25.73 - 25.90	
No	9,330	25.74	4.85	25.64 - 25.84	
Private Insurance					<.0001*
Yes	7,322	25.49	4.89	25.38 - 25.60	
No	13,315	25.94	4.89	25.86 - 26.02	
Residency					
- Regional					0.0234*
New York City	14,805	25.62	4.47	25.55 - 25.70	
Rest of the state	5,832	26.17	4.80	26.05 - 26.30	
- Region					<.0001***
Capital Area Region	676	26.71	5.00	26.34 - 27.10	
Central Region	253	27.41	5.60	26.72 - 28.11	
Metropolitan	4,274	25.58	0.07	25.44 - 25.72	
Western Region	629	29.10	4.51	28.75 - 29.46	

* *p-value* by t-test

** Standard Deviation

*** *p-value* by ANOVA

Table 3. 4. Age of referral for children with autism spectrum disorder in New York State Early Intervention Program, by characteristics

Characteristics	N	Age of referral (months)			
		Mean	SD**	95% CI	*p-value*
Gender					<.0001*
Male	16,374	21.19	6.36	21.09 - 21.2	
Female	4,428	20,67	6.80	21.49 - 21.8	
Race					<.0001**
Hispanic	6,877	21.08	6.31	20.94 - 21.2	
American Indian	31	22.58	6.87	20.06 - 25.1	
Asian NH	1,709	22.29	6.12	22.00 - 22.5	
Black NH	3,169	21.56	6.69	21.33 - 21.8	
White NH	7,221	20.28	6.54	20.13 - 20.4	
Other NH	399	21.20	6.55	20.55 - 21.8	
Medicaid					<.0001*
Yes	11,386	20.89	6.78	20.77 - 21.0	
No	9,424	21.31	6.05	21.19 - 21.4	
Private Insurance					0.0044*
Yes	7,402	20.91	6.22	20.77 - 21.0	
No	13,408	21.18	6.59	21.06 - 21.2	
Residency					
- Regional					0.0234*
New York City	14,892	21.02	6.69	20.91 - 21.1	
Rest of the state	5,918	21.23	5.84	21.09 - 21.3	
- Regi					0.0279**
Capital Area Region	688	21.65	5.55	21.23 - 22.0	
Central Region	261	20.59	5.77	19.88 - 21.2	
Metropolitan Region	4,303	21.26	5.86	21.09 - 21.4	
Western Region	666	20.89	5.97	20.44 - 21.3	

* *p-value* by t-test
** Standard Deviation
*** *p-value* by ANOVA

Table 3. 5. Time to evaluation for children with autism spectrum disorder in New York State Early Intervention Program, by characteristics

Characteristics	N	Time to evaluation (weeks)			
		Mean	SD**	95% CI	*p-value*
Gender					0.8511*
Male	15,493	4.41	4.85	4.33 - 4.48	
Female	4,204	4.42	4.85	4.28 - 4.57	
Race					<.0001***
Hispanic	6,535	4.77	5.17	4.65 - 4.90	
American Indian NH	30	4.53	3.20	3.34 - 5.73	
Asian NH	1,634	3.68	3.40	3.51 - 3.84	
Black NH	2,995	4.85	5.21	4.67 - 5.04	
White NH	6,858	3.98	4.25	3.88 - 4.08	
Other NH	376	4.47	2.79	4.19 - 4.76	
Medicaid					<.0001*
Yes	10,723	4.69	5.52	4.59 - 4.80	
No	8,981	4.09	3.78	4.00 - 4.16	
Private Insurance					0.0044*
Yes	7,042	4.06	3.91	3.97 - 4.15	
No	12,662	4.61	5.25	4.52 - 4.70	
Residency					
- Regional					<.0001*
New York City	14,139	4.49	5.07	4.41 - 4.32	
Rest of the state	5,565	4.21	4.11	4.10 - 4.32	
- Region					0.0002***
Capital Area Region	637	3.98	3.72	3.69 4.27	
Central Region	249	3.92	1.85	3.67 - 4.15	
Metropolitan	4,043	4.16	3.43	4.05 - 4.26	
Western Region	636	4.86	7.57	4.28 - 5.45	

* *p-value* by t-test

** Standard Deviation

*** *p-value* by ANOVA

Table 3. 6. Time to ASD diagnosis for children in New York State Early Intervention Program, by characteristics.

Characteristics	**N**	**Time of ASD diagnosis (weeks)**			
		Mean	**SD****	**95% CI**	***p-value***
Gender					0.0039*
Male	16,103	21.32	24.20	20.94 -21.69	
Female	4,373	22.58	26.02	21.81 -23.35	
Race					<.0001***
Hispanic	6,782	21.00	61.74	20.22 -23.16	
American Indian	30	23.43	23.65	14.60 -32.26	
Asian NH	1,687	18.72	22.78	17.63 -19.81	
Black NH	3,123	20.87	25.43	19.98 -21.76	
White NH	7,114	24.01	25.60	23.42 -24.61	
Other NH	391	23.05	24.32	20.63 -25.46	
Medicaid					<.0001*
Yes	11,203	22.52	25.84	22.05 -23.00	
No	9,281	20.46	22.97	19.99 -20.93	
Private Insurance					0.0218*
Yes	7,310	21.06	24.03	20.51 -21.62	
No	13,174	21.88	24.91	21.45 -22.30	
Residency					
- Regional					0.0001*
New York City	14,707	20.85	25.04	20.45 -21.26	
Rest of the state	5,777	23.46	23.33	22.88 -24.06	
- Region					<.0001****
Capital Area Region	669	24.37	19.92	22.86 -25.88	
Central Region	255	32.58	25.23	29.46 -35.67	
Metropolitan	4,194	20.35	22.39	19.67 -21.02	
Western Region	659	38.84	24.58	36.96 -40.72	

* *p-value* by t-test
** Standard Deviation
*** *p-value* by ANOVA

Table 3. 7. Comparison age at ASD diagnosis and age of referral (in months) for children in New York State Early Intervention Program, by geographic location: New York City (NYC) and Rest of the State (ROS)

Characteristics	**NYC**		**p-value**	**ROS**		**p-value**
	N	**Mean**		**N**	**Mean**	
Age at ASD diagnosis						
Gender			0.0237			0.5664
Male	11,596	25.67		4,563	26.16	
Female	3,166	25.45		1,215	26.25	
Race/ ethnicity			<.0001			0.0026
Hispanic	5,733	25.63		1,092	26.01	
American Indian	24	27.13		7	28.57	
Asian NH	1,453	26.39		239	26.56	
Black NH	2,665	25.96		465	26.98	
White NH	3,421	24.77		3,672	26.14	
Other	253	26.09		142	26.53	
Medicaid			0.0870			0.0007
Yes	9,475	25.68		1,798	26.49	
No	5,292	25.52		3,982	26.03	
Private insurance			<.0001			0.0581
Yes	4,435	25.12		2,846	26.05	
No	10,332	25.84		2,943	26.29	
Age of referral						
Gender			<.0001			0.4037
Male	11,669	21.19		4,630	21.17	
Female	3,178	20.40		1,234	21.40	
Race/ ethnicity			<.0001			<.0001
Hispanic	5,764	20.98		1,098	21.57	
American Indian	24	22.04		7	24.43	
Asian NH	1,457	22.32		244	22.04	
Black NH	2,681	21.36		476	22.63	
White NH	3,443	19.68		3,734	20.81	
Other	254	21.19		144	21.18	
Medicaid			0.0001			0.0874
Yes	9,525	20.86		1,826	21.02	
No	5,328	21.30		4,040	21.31	
Private insurance			0.0014			0.2272
Yes	4,466	20.75		2,895	21.13	
No	10,387	21.13		2,971	21.31	

Table 3. 8. Comparison time to evaluation and time to ASD diagnosis (in weeks) for children in New York State Early Intervention Program, by geographic location: New York City (NYC) and Rest of the State (ROS)

Characteristics	**NYC**		**p-value**	**ROS**		**p-value**
	N	**Mean**		**N**	**Mean**	
Time to evaluation						
Gender			0.5113			0.2033
Male	11,073	4.48		4,347	4.24	
Female	3,023	4.55		1,165	4.08	
Race/ ethnicity			<.0001			0.4224
Hispanic	5,493	4.89		1,027	4.17	
American Indian	24	4.71		6	3.83	
Asian NH	1,397	3.68		230	3.72	
Black NH	2,537	4.93		446	4.42	
White NH	3,298	3.73		3,517	4.22	
Other	239	4.50		136	4.45	
Medicaid			<.0001			
Yes	8,972	4.72		1,717	4.55	
No	5,129	4.10		3,797	4.06	
Private insurance			<.0001			0.0296
Yes	4,269	4.04		2,733	4.09	
No	9,832	4.69		2,781	4.33	
Time to ASD diagnosis						
Gender			0.0237			0.7675
Male	11,520	20.39		4,509	23.84	
Female	3,142	22.64		1,215	22.51	
Race/ ethnicity			<.0001			<.0001
Hispanic	5,701	21.00		1,066	21.02	
American Indian	24	22.50		6	27.17	
Asian NH	1,442	18.30		237	21.65	
Black NH	2,647	20.84		464	21.31	
White NH	3,411	22.91		3,660	25.14	
Other	251	21.81		139	25.26	
Medicaid			0.0870			<.0001
Yes	9,385	21.91		1,783	25.89	
No	5,283	19.02		3,943	22.50	
Private insurance			<.0001			0.3406
Yes	4,425	19.75		2,845	23.26	
No	10,243	21.35		2,881	23.85	

Figure 3.2. Trends in age at autism spectrum disorder diagnosis (*p=0.4239*) and age of referral (*p= 0.8642*) for ASD children in New York State Early Intervention Program, from 2005 to 2014

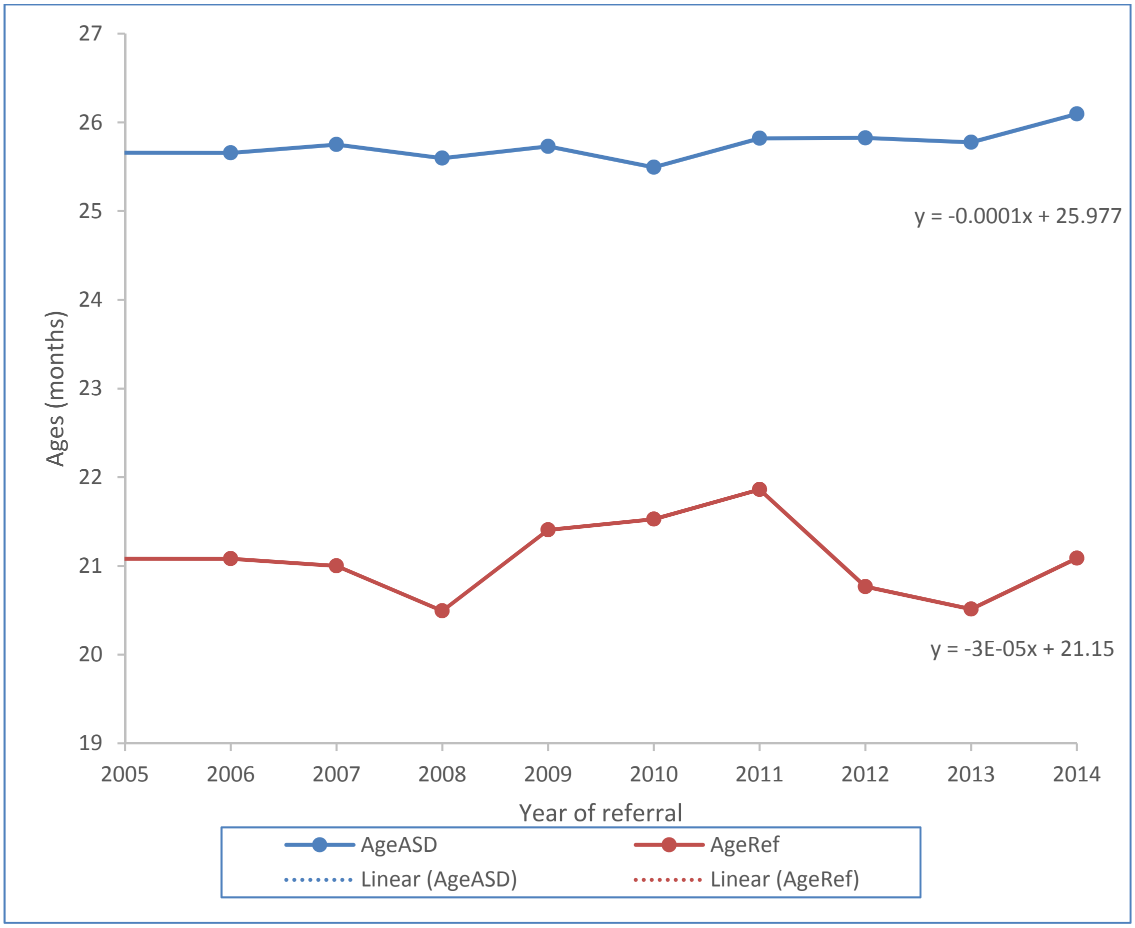


Figure 3.3. Trend in time to evaluation for children who diagnosed with autism spectrum disorder in New York State Early Intervention Program, from 2005 to 2014 (*p=0.8368*).

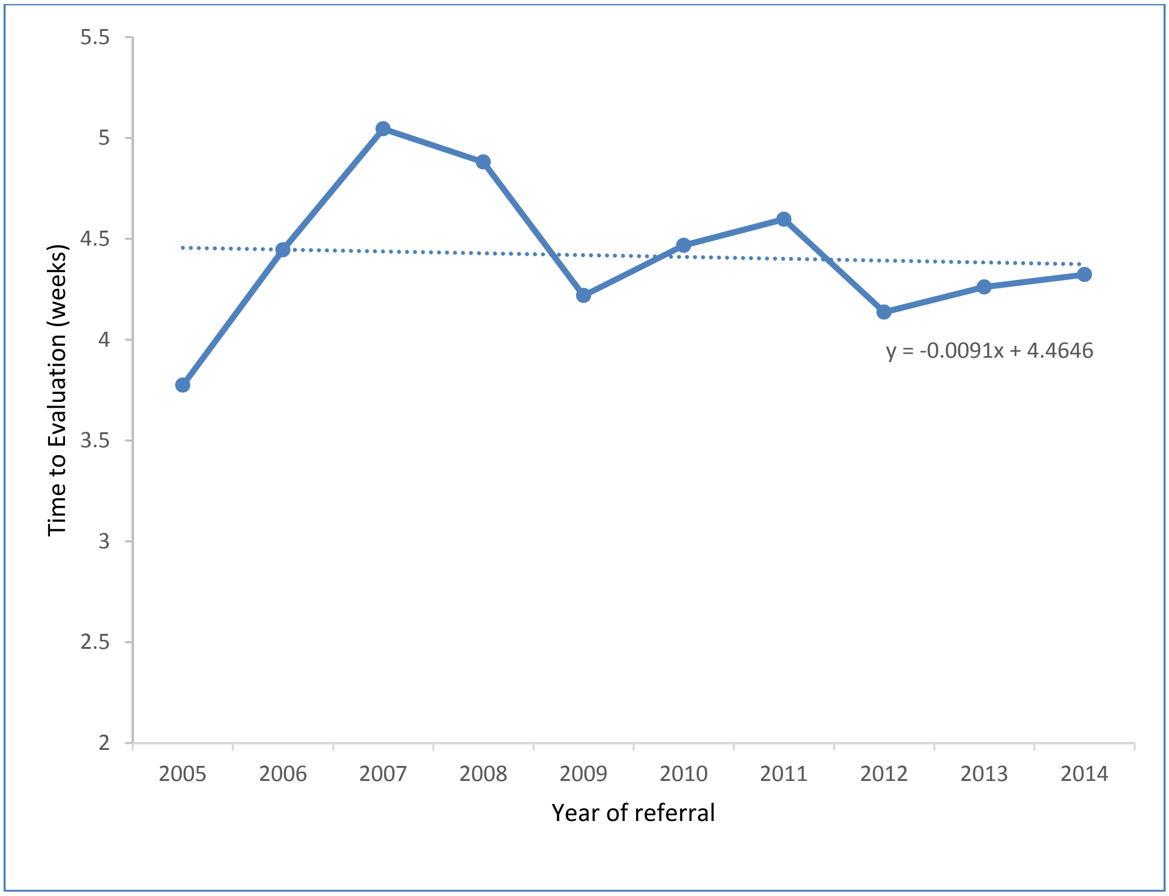
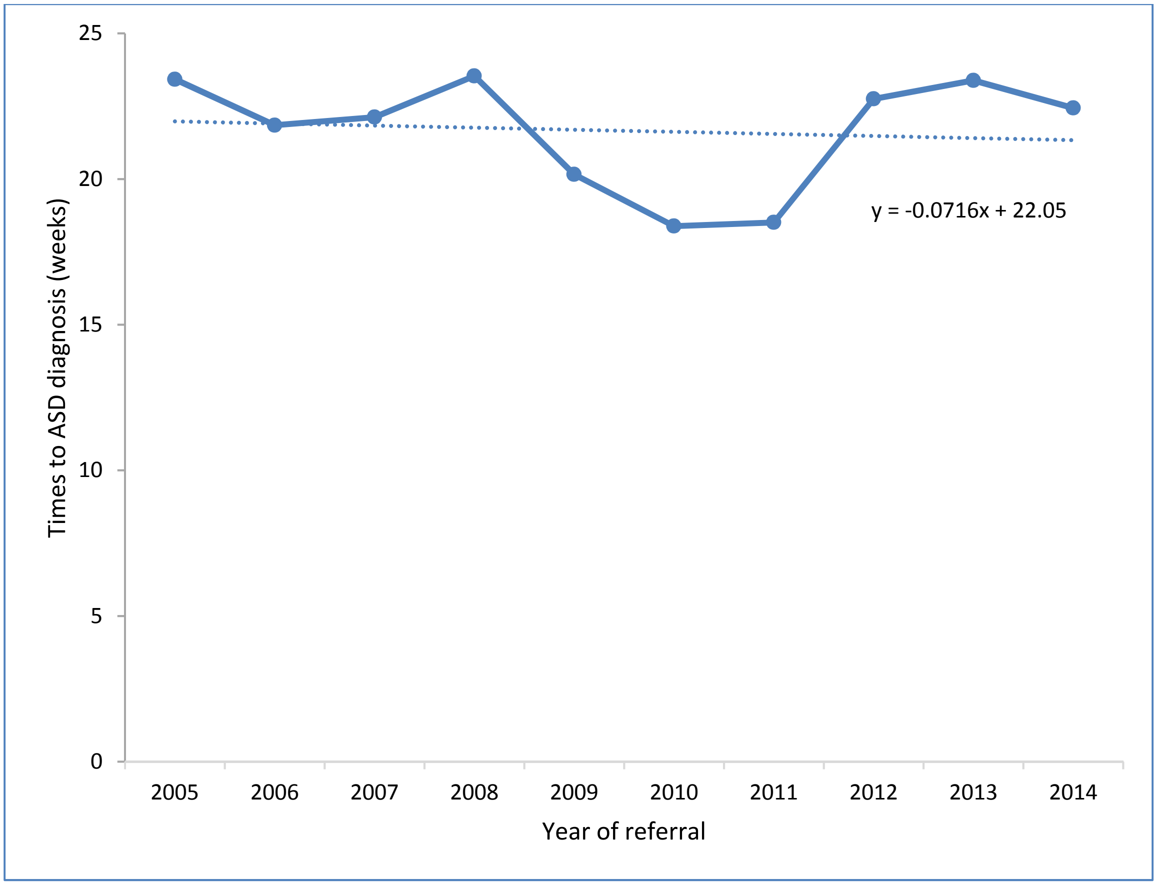


Figure 3.4. Trend in time to diagnosis for children who diagnosed with autism spectrum disorder in New York State Early Intervention Program, from 2005 to 2014



CHAPTER 4.

CONCLUSIONS

4.1. Summary

Autism spectrum disorder (ASD) is a public health concern given the large number of cases reported[1–3] and the impact on health and wealthness of affected children and their families.[4–10] No medication has been proven to cure core symptoms of this condition[11]. The etiology of ASD is still undetermined which has led to great difficulty in diagnosis and determining as well as treating ASD. Impairments of communication, social interaction and behaviors shown by a child with ASD require lengthy and intensive intervention, which can have high cost in terms of money and stress. Because of the high cost and the life-long impact, ASD is a concern shared by families with individuals with ASD as well as local communities and nations, given the impact on the economy and the need for lifelong support.[12–14]

Increasing ASD prevalence has been reported from many studies with different populations, geographical locations and methodologies. Results show that ASD prevalence varies by sociodemographic characteristics of affected children, parents and severity of this condition.[3,15,16] While the current upward trend of ASD has continued, understanding the trends and the characteristics of individuals with ASD may lead to a better understanding of risk factors and could enhance diagnosis and intervention for ASD. It is important to conduct incidence studies as information on this would enable collection of exposure prior to disease; however, these types of studies require many resources in terms of both time and funding. For this study of ASD among young children enrolled in the New York State Early Intervention Program (NYSEIP), a retrospective cohort analysis is preferred due to practical reason. This study -for some instance- enables an assessment current burden of ASD which is of interest for policy planning.[17,18]

Diagnosis of ASD is made by a professional or a team of professionals through a series of behavioral evaluations. Research has shown that ASD can be reliably diagnosed by 18 months; however, many children with this condition are diagnosed on average around four years old.[1] Early diagnosis is important to ensure a child with ASD receives treatment as early as possible because intensive intervention that starts in early life has been demonstrated to result in a better outcome. Delaying diagnosis translates into a delay in intervention and loss of opportunity to intervene when the child's brain development is most active between birth and three years old. This lost time could result in higher costs of treatment over the life time, including medical, behavior and education. Having an ASD diagnosis may also facilitate access to evidence-based ASD behavioral treatments such as Applied Behavioral Analysis (ABA).

In the United States, routine developmental screening with appropriate ASD diagnosis and treatment for children through three years of age is available through state-coordinated early intervention services. This program provides a comprehensive multidisciplinary evaluation as well as support and services for children with suspected developmental delay and their families. ASD diagnosis is not required to establish eligibility in this early intervention program (EIP). Children may receive an ASD diagnosis in EIP. In New York State, the New York State Early Intervention Program (NYSEIP) has been providing services to children with developmental delays, including ASD, since 1993.

This study examined the prevalence of ASD, analyzed the trends, assessed children's sociodemographic characteristics and examined timing of ASD diagnosis among children who enrolled in the NYSEIP. Secondary data from the New York State Early Intervention data systems was used. The systems include NYEIS (New York State Early Intervention System) -a centralized web-based system that electronically manages the NYSEIP administrative tasks and was designed to support the NYSEIP's services- and the legacy data system: KIDS (The Kids Integrated Data System).

Published studies on ASD prevalence among children in state EIP, the NYSEIP, is limited. Most prevalence studies have used samples from the general populations or clinical settings. In this study, ASD prevalence trends were analyzed to determine whether ASD prevalence increased, decreased or remained stable, by looking at children’s characteristics such as gender, race/ethnicity, insurance status and geographical location.

The time-trend design employed in this study is a form of longitudinal ecological study, and was intended to provide a dynamic view of ASD status in the NYSEIP. Data were collected from the NYSEIP from 2005 to 2014 referral year, to look for trends and changes. Like other ecological studies, the data collected can be used to generate hypotheses for further research, rather than demonstrating causality.[19] Trend data about prevalence of ASD can be used by public health professionals to assist in healthcare needs assessments, service planning, and policy development. In addition, examining data over time also makes it possible to predict future frequencies and rates of occurrence.

Investigating age at ASD diagnosis was performed at the second part of the study, as well as age of referral, time of evaluation and time of ASD diagnosis for children diagnosed with ASD who enrolled in the NYSEIP. Similar to ASD prevalence in general, age at ASD diagnosis also varies by gender, race/ethnicity, socioeconomic status and geographical locations.[20–36] Beyond general studies of ASD diagnosis age, there have been few in-depth at risk population-based studies of ASD diagnosis age by child’s sociodemographic characteristics. Past studies were mostly conducted in general population with small sample size and have not accounted for variation within geographic location in New York State. In this study, ASD diagnosis was compared across gender, racial/ ethnic groups, insurance status, residential location and ASD subtype, in at risk children who enrolled in the NYSEIP from 2005-2014 referral year. This study also compared age of referral, length of time between referral to evaluation and length of time between referral to have ASD diagnosis across sociodemographic variables. International Classification of Diseases (ICD 9) and ICD 10 were used as ASD diagnostic criteria in the data source. More detailed description on methods and findings of each part of the study are presented in the following sections.

Specific Aim 1

The first part of the study was aimed at examining the prevalence of ASD among children 0-36 months enrolled in the NYSEIP, investigating the trends of ASD prevalence by children's demographic characteristics and identifying children's characteristics associated with ASD diagnosis. In the ten-years period of study, the prevalence of ASD increased about 178.9%, with a 7.7 % annual change. The increasing prevalence of ASD found in this study was comparable with most of prevalence studies on this topic where the number of ASD cases has been markedly increased across subgroups of demographics: gender, race/ethnicity, insurance status and geographical locations.

The interactions between those variables and time are significant, which imply that the increase in ASD prevalence was associated with time. During this ten-year period, factors such as increasing awareness of autism in the community (including parents and health providers), better detecting of suspected children, better ability to diagnose, better reporting system and increasing risk factors may have contributed. Assessing the change in risk factors was beyond the scope of this study's aims, and because the etiology of ASD is still not clear. An increasing in awareness of this condition in the local community which lead to more and earlier evaluations asked may explain some of this increase.[3,37,38] An increasing campaigns of educational programs for ASD among health professionals, particularly in concentrated places such as big cities, has led to increased attention for children with symptoms related to ASD which has led to increasing diagnosis of ASD at younger age.[34,39] Increases in state and national funding has led to increasing awareness and positively impacted quantities and quality of services.[40–42] From this perspective, the variation of increasing rates across regions or counties may also mean that growing public awareness has not been evenly distributed across New York State. Health providers including evaluators and early intervention providers may less available in certain locations. Future research between capacity and diagnosis of ASD would be important.

As in other epidemiological studies, this administrative and services data suggest that better detection cannot fully explain the profound and continuing increase in prevalence. Whether ASD is a disease with more affected individuals or more detected ones is a question that this study may not fully answer, not only because of the design of this study but also autism is not a simple disorder. This study, however, indicated there has been an increase in reporting in the NYSEIP. While other studies have demonstrated gaps in ASD diagnosis by race/ ethnicity, data from the NYSEIP indicated that the underserved groups were being diagnosed with ASD at similar rates as white children. Looking to previous concerns about uneven distribution of health providers across counties, efforts for increasing ASD awareness should be conducted simultaneously with increasing ability of evaluators, local health providers and local community.

Specific Aim 2

The second part of the study was aimed at to examining age at ASD diagnosis, age of referral, time to evaluation and time to ASD diagnosis among children who enrolled in the NYSEIP. There were 20,826 children who received ASD diagnosis during their time in the program. ASD diagnoses were reported and recorded using International Classification of Diseases (ICD) 9 and 10. Variables included in this analysis were gender, race/ethnicity, insurance status and geographical locations.

Children in the NYSEIP received an ASD diagnosis at 25.78 months on average. Most children were diagnosed with ASD between one and three years of age (99.66%), with more than half receiving their ASD diagnosis after age two. This results confirm that ASD can be detected at very young ages. Receiving an ASD diagnosis can help to ensure that children with ASD receive intensive evidence-based behavioral therapy. This study found that age at ASD diagnosis and time to ASD diagnosis varied by geographic region. Children who lived in Western and Central Region received their ASD diagnosis at older ages than children in other regions of the state. Local policies and resources may influence age at ASD diagnosis. Factors such as lack of physician familiarity with screening measures, lack of time and resources and failure to follow-up after a positive screening outcome have been identified as barriers to early identification of ASD.[43–51]

Participation in the NYSEIP does not require an established diagnosis of ASD to receive early intervention services. About 15% did not receive and ASD diagnosis for four months or more. While these children received services, it has been found previous studies that having the diagnosis of ASD can help children and their families in getting intensive, evidence-based behavioral therapy. Current clinical guidelines recommend about 25 hours of services[52];therefore, the loss of five months would equate to almost 500 hours of intensive services.

Data for this study have been taken from administrative data. The completeness of ASD reporting is unknown and beyond the scope of this study. Differential reporting by region could lead to spurious conclusions. Future research would need to include efforts to reach out directly to local programs to determine if children were diagnosed with ASD but not reported in the child's report.

Another significant finding is the delayed in ASD diagnosis for children in the NYSEIP suggesting that evaluation for ASD symptoms in these at risk children needs to be improved. Responsible persons (for example, ongoing service coordinators) may need to collaborate with other treatment providers to ensure that a suspected ASD child will not miss their opportunity to receive evidence-based ASD treatments because of delayed ASD diagnosis.

4.2. Limitations

One limitation of this study is the data source use of administrative. Limitations of using administrative data including missing data may have led to underestimation of the main outcome. ASD diagnoses were not independently confirmed which may affect the reliability of ASD diagnosis and true ASD prevalence in the program. However, NYSEIP data especially NYSEIS is a state-of-the-art data base and that is continually updated. Moreover, number of missing data in this study is considered as missing completely at random.

Another limitation is the inclusion of several variables that have been reported previously as being significant associated with ASD prevalence, early diagnosis and intervention. Those factors are income, occupation, and education, pre-natal and post-natal information (birth weight and type of delivery), family history of autism (i.e. sibling autism status), type of healthcare professionals who make the diagnosis, type of local providers and frequency and tools for evaluation.[53–66] This study did not assess all of those factors, it is important to remember that there are many factors that affect ASD prevalence and the timing of diagnosis.

4.3. Strengths

Despite of the limitation of using administrative data, the strength of this research is on the data source: NYSEIP data systems which is large and has extensive data collected over a long period of time. The use of this data source allows to analyze different variables of interest with no additional cost. More importantly, the time length of data coverage allows to conduct time-trend analysis.

Another strength of this study is that the opportunity to assess the most density and high diverse population: New York State. As this state is not part of the national surveillance study of ASD, this study may provide additional information on the features of ASD prevalence in the US.

4.4. Future Directions

This study of ASD prevalence and the trends and timing of ASD diagnosis has raised more questions and next steps for research and policy. Continued observations on trends of ASD prevalence would be useful to monitor patterns and identify groups of individuals that are diagnosed at greater or lesser frequency than other populations. This study also supports specific, target outreach to local communities and local organizations in Western and Central NYS to increase awareness of ASD and ensure adequate capacity for ASD screening and diagnosis.

Another future research consideration is the change in the diagnostic criteria for ASD from the fourth to fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). Other studies have been suggested an on ASD prevalence that would lead to a decrease because of previous diagnostic criteria have been excluded.[67–75] Future continued time-trend studies may allow for more systematic analysis of the impact with more time. This study was limited in that the NYSEIP serves children under the age of three. Follow up of these children in their later ages may provide broader picture on ASD prevalence and impact of early intervention for them. In addition, comparing ASD prevalence in older age groups over time would be important to asses ASD burden in NYS. In addition, conducting a research by linking early-intervention program data with population-based vital statistics would give more robust and broader picture of ASD trends and be a valuable resource to plan and develop health and educational service needs.

While this study shows that there are not meaningful differences across race/ ethnicity, there are regional differences found on prevalence of ASD, time to evaluation and time to ASD diagnosis. Urbanicity has been demonstrated as an affecting factor for early screening. While a study on the accessibility of early intervention providers in NYS has evaluated the total numbers of local providers available, the analysis did not focus on providers who serve children with ASD.[76] That study suggested that distance to providers can affect the numbers of children served and type of services delivered. In line with that study, future research using similar methods may be conducted to evaluate whether similar patterns hold for children with ASD. Next study using spatial epidemiology analysis may be useful to evaluate the participation in the NYSEIP, how certain treatments are delivered and availability of other ASD programs across counties in NYS.

In addition, questions such as what are factors that hinder certain regions on early detection and diagnosis of ASD cases, how do professionals perform evaluations and what kind of evaluation tools are used are raised and need to be investigated. Using similar or different data sources and methods of study would clarify some of the new raised and unanswered questions in this study. Some hypotheses generated from this time-trend analysis are noteworthy.

While participation in the NYSEIP is voluntary, the extent on how families in New York State utilize public programs has never been studied. A study of factors associated with participation in the NYSEIP across regions and counties may also be important to understand barriers that may exist for families to interact with providers within the NYSEIP.

These future steps are in line with suggestions made by New York State Interagency Task Force on Autism to increase the utilization of ASD screening by pediatricians and early intervention providers and to disseminate information on early assessment and diagnosis of ASD to families.[41] The Task Force was charged with crafting a response that would improve interagency coordination of services, maximize the impact and effectiveness of services and agency functions. Since New York State Department of Health is one of the members in this Task Force, collaboration with other members as well as private organizations will support ASD individuals in NYS.

4.3. Conclusion

Monitoring ASD prevalence among children across different socioeconomic characteristics provides a dynamic view of children’s and families’ experience and the early intervention service delivery system. Tailored information dissemination efforts, including the importance of early screening and early intervention, need to be increased among healthcare professionals, early intervention providers and communities. These findings add to a growing body of evidence that ASD prevalence has been increasing across all groups of individuals and to the literature on early diagnosis and intervention of ASD. This study hopefully contributes useful inputs to improve the NYSEIP and by design, was intended to generate several important hypotheses for future research.

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