Sociodemographic and Diagnostic Comparisons Between Children Identified with Autism With and Without a Previous Autism Diagnosis

By

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(Under the direction of Dr. Zolinda Stoneman)

ABSTRACT

Some children that may display the behaviors associated with autism have not been diagnosed with the disorder. These children are at risk for not receiving treatments that have been shown to improve outcomes in children with autism. This study used population based surveillance data to investigate sociodemographic and diagnostic differences between children that had a diagnosis of autism before they came into the surveillance system and children that did not have a diagnosis of autism before they came into the surveillance system. This study also included a review of the records of children without a previous diagnosis of autism. Results showed that there were differences between the two groups in maternal age, maternal education, race, age of child, abstraction source, and primary exceptionality.

INDEX WORDS: Autsm, Epidemiology, Sociodemographic Factors, Special Education

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LITERATURE REVIEW

Autism is a pervasive developmental disorder, which is believed to affect two to six out of every 1000 children around the world (Chakrabarti & Fombonne, 2001). The disorder is characterized by impairments in three different areas of functioning: unusual social behaviors, communication, and stereotypic behaviors/unusual interests. The disorder occurs more frequently in boys, with estimated ratios of boys to girls ranging from 1.33:1 to 16:1 with a median value of 2.55 (Fombonne, 1998). There has recently been public concern that the rates of autism are rising and several aspects of the environment have been implicated such as environmental toxins, MMR vaccines, and retinoids (CDC, April, 2000; London and Etzel, 2000). The public has expressed concern about the increasing rates of autism that have been shown in several studies (California Department of Developmental Services (DDS), 2000; Bertrand et al., 2001). This concern is reflected by articles in popular press magazines (Newsweek, 2000; Wired, 2001), discussions in congress about the issue (The Children's Health Act of 2000, 2000), and congressional panels including the Congressional Coalition for Autism Research and Education. Because of this concern there has been increased interest in the epidemiology of autism.

As there is no biological marker for autism, the diagnosis of autism is made from behavioral observations. The use of behavioral criteria to establish a diagnosis yields diagnostic variation between evaluators and is influences by clinician interpretation and

experience. For instance. examiners could diagnose of autism when they do not have the disorder (false positive) or the examiner may fail to diagnose a child who actually does have the disorder (false negative). This paper will focus on a group who meet behavioral criteria for autism, but were not given this diagnosis by a diagnostician. In the case of autism, early and accurate diagnosis may provide the child with appropriate early intervention. Failure to receive early intervention services indicated for children with a diagnosis of autism can have serious ramifications upon achievement of long-term outcomes.

Ramifications of a misdiagnosis

In a disorder like autism where early intervention is essential, misdiagnosis could exclude a child from the early intervention services that could greatly improve their outcome (Dawson, 1997; Rogers 1998; NAS report 2001). A report recently distributed by the National Academy of Science Commission on Behavioral and Social Sciences and Education (2001) recommends that services should begin as soon as a child is suspected of having an autism spectrum disorder and should include a minimum of 25 hours a week, 12 months a year. In the absence of an autism diagnosis a child may not receive this type of intensive behavioral treatment.

Early identification is also important for family functioning. Without education about how to best structure the life of their child with autism, families may have difficulties incorporating the child into their typical family patterns. However, if patterns are changed, it could result in the reallocation of family responsibility to older siblings that could result in resentment. An early intervention specialist could work with the family in establishing and maintaining behavioral treatments that make it easier for a

child with autism to understand and function within the family environment. This type of early intervention program often provides family support services, in-home help and respite services. This type of assistance improves the outcomes of both children with autism and their families (Allen & Mendelson, 2000). When children with autism are identified early, parents can use this information when considering having another child. The risk of having another child with autism is 5%, which is 100 times higher than the risk in the general population (Baird et al., 2001)

Causes of misdiagnosis

Diagnosis of autism is highly reliable for "prototypical autism" but there are several aspects of the disorder that make it difficult to discriminate from disorders like language delay and mental retardation. Differential diagnosis is complicated by the range of developmental levels represented by people needing assessment, the lack of normative scaling of autism scales, the rarity of repetitive and compulsive behaviors during observation sessions (Lord, 1989), and difficulties controlling for language delay (Lord, 1997). Diagnosis may also be difficult because of certain characteristics of people with autism that make them hard to assess, such as unusual developmental profiles, attentional problems, and behavior problems (Volkmar & Cohen, 1997).

A child with autism could also be missed due to physician error. Some physicians are insensitive to language regression as a sign of serious developmental problems and since autism occurs more in boys than girls, may dismiss delayed language development as being typical for boys (Rapin, 2001, Siegel, Pliner, Eschler, & Elliott, 1988). The involvement of physicians is important because Siegel et al. (1988) found that 92% of parents of children with autism first reported concerns about the development of their

child to their primary care physicians and initial diagnosis was most likely to be made by pediatricians or teams of two or more evaluators. There was a 13-month interval between when the parents first reported concerns about their child and when their child received a diagnosis. If the child had received the diagnosis earlier they could have been receiving important early intervention services during that time.

Causes of the rising rates of autism

In response to concerns about an "epidemic of autism", Fombonne (2001) states that the multiple methodologies of current epidemiological studies of autism make it impossible to detect secular increases in the rates of autism. He states that the increased rates reflect a broader concept of autism, people with normal IQ's receiving the diagnosis, changes over time in the diagnostic criteria, and better training in the diagnosis of autism. In a letter to the *British Medical Journal,* Heussler et al. (2001) discuss the results of a focus group that reviewed the criteria used to diagnose autism in a 1970 study. They then revised the criteria to reflect what is known about the diagnosis of autism in the literature. They used the revised criteria to re-review the records from the 1970 study and found a prevalence rate close to the current rate. They suggest that the recent changes in the diagnostic criteria for autism are responsible for the increase in the prevalence of autism seen in recent years. Fombonne (2001) suggests that future studies should consistently use the same case definition and identification method, sample children who are in the upper range of school age years, control for changes in the population, and use adequate sample sizes.

Another method for examining the possible increase in autism rates is to screen adults for autism and see how many were missed. In a study on an adult psychiatric

population Nylander and Gillberg (2001) attempted to estimate the prevalence of Autism Spectrum Disorders (ASD) in a population of people receiving psychiatric services. The authors looked at this population because they believed that the definition of ASD has expanded in recent years and there may be adults who have an ASD but do not have a diagnosis of ASD. Because psychiatric disorders and symptoms are common in populations of people with high functioning autism and Asperger's, the authors thought that they would be more likely to find adults with ASD in this population. They screened 1,398 psychiatric patients and from that population 31 failed the screener and were evaluated for ASD by the first author. After clinical evaluation, 19 patients received an ASD diagnosis. Most of the people diagnosed with an ASD were being treated for psychosis and personality disorders. The authors stated that these diagnoses reflect co-morbidity as opposed to misdiagnosis, but would still result in an undercount of ASDs. The authors concluded that a minimum of 1.4% of all patients receiving psychiatric outpatient care have an ASD. The presence of undiagnosed ASD in adult psychiatric patients could explain why the rates of autism are higher in younger children than in adults.

Although the mechanisms that result in children with autism being missed through developmental screenings and assessments are important, there is little research on the characteristics of the group of children who are missed when assessments are conducted. Information about this group of children could illuminate the social, diagnostic, and biological mechanisms that drive this misdiagnosis. Although there is little information on why children with autism may not receive the diagnosis, there is information on the factors that may drive this phenomenon and how they relate to the

general population of children and children diagnosed with autism. The descriptive information presented in this review of the literature will present information that can be used to compare children with autism who do not receive a diagnosis of autism to children that do receive a diagnosis. The information presented in this literature review will include general epidemiology of autism, epidemiology of autism in the US, sociodemographic characteristics, information about the process of diagnosis, information on the age at which children are first diagnosed with autism, comparisons between the school and non-school diagnostic processes, and information on special education eligibility categories.

General Epidemiology

The findings of research on the epidemiology of autism have varied widely. This variation could be due to inconsistencies in methodology, different definitions of the disorder, the inclusion of different disorders like atypical autism, Asperger's disorder, and pervasive developmental disorder-not otherwise specified (PDD-NOD), and real differences in the prevalence of autism in different areas and change over time in the rates of autism (Fombonne, 1998; Wing, 1993). Most studies investigating the epidemiology of autism used a two-stage design. The first step involved identification of children who possibly had autism through a screening procedure. The second step involved assessments by professionals in the field (Fombonne, 1998). The assessments were conducted using several different instruments depending on the criteria that the researcher was using. Table 1 shows diagnostic criteria as outlined by Kanner, Rutter, *DSM-III*, and *DSM-IIIR* (Wing, 1993). Prevalence rates of autism using these criteria range from .7 per 10,000 to 15.5 per 10,000 with a median value of 4.8 (Fombonne,

1998). More recent studies using *DSM-IV* or *ICD-10* criteria have found rates between 2-6 per 1,000 (Chakrabarti & Fombonne, 2001)

History of prevalence studies in the US

There have been four studies on the prevalence of autism done in the US (Burd, Fisher, & Kerbeshian, 1987; Bertrand et al., 2001; Kirby, Brewster, Canino, &Pavin, 1995; Ritvo et al., 1989). These studies indicated prevalence rates of autism ranging from .25/1000 to 4/1000. The study by Burd, Fisher, & Kerbeshian (1987) was done in North Dakota. The methodology involved a two-step procedure where all facilities that were believed to see children that could have infantile autism between the ages of 2-18 were surveyed by mail and requested to review the *DSM-III* criteria and report if they had any children that fit the autism diagnosis. These children were then observed by the authors for a developmental evaluation that included a structured interview, a psychiatric evaluation, an educational evaluation, and a speech evaluation. The clinical decision was made based on the *DSM-III* criteria. The authors reported a prevalence rate of 1.16 per 10,000.

The study by Bertrand et al. (2001) was done in New Jersey. The methodology involved a two-step process. In the first step all children between the ages of 3-10 in the year 1996 who had signs of autism were identified by screening the school, medical and other source records. In the second step clinicians trained in the assessment of autism evaluated the identified children using the *DSM-IV* criteria to confirm diagnosis. The prevalence rate for children with autism was 40 per 10,000.

The study by Kirby et al. (1995) was done in northwest Arkansas. The study involved abstraction of records and review of records by program staff. Using ICD-9

criteria they identified 6 cases of autism/pervasive developmental disorder that had been identified before the age of four that were born between the years 1985-1987. The prevalence rate obtained using this method was .4 per 1000.

The study by Ritvo et al. (1989) was done in Utah. This study also had a two-step procedure. In the screening step 4 different methods were employed to find people with possible autism. The methods for finding people included using people with autism identified though the researchers' contacts with parent groups, voluntary referrals obtained through a media campaign, solicited referrals from practitioners, and a record review at residential facilities. In the second step the authors applied the DSM-III criteria to the records of all people obtained in the study and, if the person was determined not to have autism by more than one rater on more than one scale; then they were excluded from the study. The people who were not excluded were observed by the authors and diagnosed using the DSM-III criteria. The prevalence rate obtained through this data was 4 per 10,000.

Sociodemographic factors

Several sociodemographic factors have been associated with developmental disabilities in the literature. The factors that will be included in this study are maternal age, maternal education, and race. These factors are important to the diagnosis of autism for several reasons. Mothers are often the ones who take their children to the pediatrician and are the ones who report developmental problems. Maternal factors also contribute to the type of parental involvement and level of interface with diagnosticians and school systems. Race is important because it affects the perception of professionals within the health care system and their response to children (Coard & Holden, 1998).

Maternal Age

Maternal age as a factor related to prevalence of autism has been investigated in the literature. There is disagreement about the relationship between maternal age and autism. Gillberg (1980, 1983) found a significant relationship between maternal age and autism, while others have not found a significant relationship between maternal age and autism (Gonzaga, June 2001; Juul-Dam, 2001; Mouridsen, Rich, & Isager, 1993; Steinhausen, Gobel, Breinlinger, & Wohlleben, 1984). Gillberg's (1980) sample of mother's of children with autism had a mean age of 30.7 compared with 26.0 in the general population ($p<.001$). Gillberg may have obtained significant results due to a small sample size ($n=20$) or an overrepresentation of people with autism who had IQ's in the 50-70 range (Tsai & Stewart, 1983).

Maternal Education

Maternal education is highly predictive of the types of health and education services a child receives (Leventahl, Brooks-Gunn, McCormcik, & McCarton, 2000). In a study on the heath care patterns of infants enrolled in the Infant Health and Development Program, Leventhal et al. (2000) looked at predictors of membership into four different types of health care groups. Children whose mothers had lower education levels were most often in the basic health group, which included doctor visits only. The other groups included a mix of specialized doctor visits, educational services, and psychosocial services. Because the children who had mothers with lower education were not receiving educational services, they were more vulnerable to cognitive delays. A follow up of these children found that they did in fact have lower IQs than the total group after controlling for income. The relationship between service use and maternal

education is important to consider because a child with developmental delays indicative of autism could be missed if they were not observed in the physicians office or in an educational program.

Studies have also shown that parent's reports of their concerns about their child's development improve the efficiency of instruments designed to detect developmental disabilities (Glascoe, 1997, 1999). Mothers with less education may have problems communicating with health professionals for several reasons. The mothers may be illiterate and, if given a paper and pencil questionnaire, they may not answer the questions accurately. Glascoe (personal communication, Febuary, 20, 2002) reported that certain questions often asked by pediatricians may cause problems. For instance only 50% of parents questioned knew what the word "development" meant. Only 2% of parents would respond to questions like, "Do you think your child has any problems?" or, "Are you worried about your child's development?" Also, some of the parents that had not reported their child's developmental problems to a pediatrician reasoned that pediatricians are the experts and should be the ones to tell the parents about problems.

Race/Ethnicity

Race is another sociodemographic factor that will be explored in this study. Although autism occurs in all racial groups, the interaction between race and obtaining a diagnosis is unknown. This is because many of the areas where epidemiological studies of autism have been conducted do not have a lot of racial diversity (Sweden, France). Gonzaga et al. (2001) found that race was significantly associated with non-isolated autism (autism with a co-existing developmental disability). Ritvo et al. (1989) and

Ritvo, Cantwell, & Johnson (1971) found no correlations between the distribution of autism and race.

Some studies considering the diagnostic process have considered ethnicity as a variable. In a study by Glascoe (1997) the only significant demographic difference between parents who were appropriately unconcerned about their child's development and parents who were inappropriately unconcerned about their child's development was that the inappropriately unconcerned group was more likely not to speak English at home. It is important to note that this result was found even though the tests were administered in Spanish to Spanish speakers. The author concludes that because Spanish-speaking parents may be less likely to accurately report their child's developmental problems, a screener should be used in combination with parent report in this population. Cuccaro et al. (1996) sent out two of four case studies to different types of professionals that worked with children with developmental disabilities. The cases were black or white and high or low SES. One case description portrayed a child with autism and one description portrayed a child with attention deficit hyperactivity disorder (ADHD). The professionals were asked to give the child a diagnosis based on the information given which included race and SES information. The professionals' perceptions of the developmental disorder of the child were not significantly influenced by race.

Age at Diagnosis

In a study by Siegel et al. (1988) the mean age at which parents reported concerns was 18.3 months, the mean age at which children received their initial diagnosis was 30 months, and the age at which children received a definitive diagnosis was 54 months. In a study by Howlin and Moore (1997) 97% of parents reported recognizing

problems when their child was 3 years old but only half had received a diagnosis by age 5 years. In a more recent study, the average age at diagnosis for children with autism is 30.0 months (Chakrabarti & Fombonne, 2001). As the classification of pervasive developmental disorder moves into the less severe range (Asperger's) the age at diagnosis moves upward. Children may be diagnosed after the age of 24-30 months because their social and communicative behaviors associated with autism are less severe and less noticeable at this earlier age. At 24-30 months a child should use and understand 3 word phrases and engage in pretend play (Goldson & Hagerman, 2001), and these qualities make it easier to tell if a child's communication and social behavior is different from normal perhaps reflecting a diagnosis of autism.

Access to heath care

Studies indicate that there are socioeconomic and racial differences in the types of care that people access (Fiscella et al., 2000). Leventhal et al. (2000) state that the most powerful correlates of service use (i.e., educational, medical, and psychosocial services) in families with young children are income, maternal education, and race. The differences in service use by and service quality available to minority and low SES groups include later enrollment in prenatal care, lower quality ambulatory services, treatment using fewer expensive technologic procedures, fewer visits to specialists, and lower intensity of care (McDonald & Coburn, 1988). Studies have also shown that children of more educated mothers are more likely to receive medical and psychosocial services than children of less educated mothers (John et al., 1995; Rosenbach, 1989). Given these findings the influence of socioeconomic status and race might also impact the detection of autism in low socioeconomic status groups. Improper developmental

assessment could result from disparities in the types of procedures that are used to assess and treat children from disadvantaged groups.

Black children are less likely than white children to have a regular source of care that provides a connection to the health care system (The Morehouse Medical Treatment and Effectiveness Center, 2000). As reported by Siegel (1988) 92% of parents first reported concerns about their child's development to their primary physician. If a child does not have a physician who sees them regularly and monitors their development, their problems may be perceived as transitory or a result of the child's environment. This could lead to a delay in the child's referral to a developmental specialist for testing and a diagnosis of autism. Therefore differences in the use of physicians' services could result in differences in the early detection and treatment of autism.

Another barrier to accessing mental health care for black families is the way that many black families may perceive their treatment by physicians. A survey of the public perceptions of the racial disparity in health care conducted by the Kaiser Family Foundation (1999) found that 65% of blacks reported concern that they would be treated unfairly because of their race and 35% of blacks reported actually being treated unfairly because of their race. If people do not trust their health care provider, they may also be less likely to report their concerns about their child's development. In addition, they may be less likely to take the advice of health care providers. This combination of phenomena would lead to a low reporting rate and low adherence to the advice of health care providers.

Fiscella et al. (2000) describe why children from disadvantaged families have less access to health care. The barriers to health care include health care affordability,

geographic access, transportation, education, knowledge, literacy, health beliefs, competing demands including work, and childcare. Highlighting the access issues involved in mental health care, 45% of black respondents reported not having enough doctors and health care providers near where they lived was a major problem. These barriers are important to consider when investigating why children with autism may not be diagnosed because they illuminate that some children may not get the proper follow up assessments to investigate developmental concerns related to ASD. Inability to use the services offered by non-school sources could result from lack of education, transportation, finances, insurance, or schedule openings.

When considering the differences in access to care, one must also consider that the majority of children enrolled in government sponsored or nonprofit sponsored preschool programs are black children from lower income homes (Brayfield &Hofferth, 1995). It is possible that specialized preschool programs like Head Start are more likely to monitor a child for abnormal development and these organizations have ties with other groups that provide developmental examinations to determine placement in special education programs.

Diagnosis of children with autism

Professionals in several different areas can diagnose children with autism using several different methods. The professionals that usually assess children with autism include developmental pediatricians, neurologists, psychologists, psychiatrists, speech-language pathologists, occupational therapists, specialized diagnosticians, special education evaluators, and physical therapists. The types of instruments include screening measures, observation schedules, and diagnostic interviews (Lord, 1997). The items on

these various instruments can be addressed in several different ways including observation of the target child, parent interview, and in the case of high-functioning children, self report. Most children thought to have autism receive psychological and communicative assessments (Sparrow et al., 1997). A psychological assessment includes assessment of intellectual functioning, developmental level, and adaptive behavior. This type of testing is used to understand the abilities of the child so that the clinician can understand the behavior of the child in the context of their intellectual functioning (Sparrow et al., 1997). Communicative assessments include standardized tests of communication and a clinical assessment of the child's receptive and expressive communication skills (Marans, 1997).

Recently, several review boards have published recommended assessment procedures for professionals. The quality standards subcommittee of the American Academy of Neurology and the Child Neurology Society recommend a three level assessment process for the assessment of autism (Filipek et al. 2000). The first level is to establish routine developmental surveillance to be administered at well-child visits. If a child shows signs of developmental problems, they should undergo laboratory investigations and a screener designed specifically for autism. If a child shows signs of autism from this screening, they should undergo a formal diagnostic and evaluation exam by an experienced clinician. Although the American Academy of Pediatrics (AAP) endorses these recommendations, they are not consistently applied in a clinical setting. The reasons that they are not applied include pediatricians' work load, the relative lack of information available to pediatricians about autism, and the insurance policies lack of reimbursement for additional well child visits needed to provide developmental

assessments or the home visits needed to implement interventions (American Academy of Pediatrics, 2001).

In the school system, children are assessed to determine their eligibility for special education services. The areas of special education eligibilities that a child could receive in the state of Georgia include: autism, deaf/blind, deaf/hard of hearing, emotional behavioral disorder, intellectual disability, orthopedic impairment, other health impaired, significant developmental delay, specific learning disability, speech-language impairment, traumatic brain injury, and visual impairment (for a description of each see figure 1) (Georgia Department of Education, 2002). For a child to be considered for one of these categories they must first receive an eligibility assessment that documents the area of the disability. Children with autism could be deemed eligible for several different categories depending on what measures are used to evaluate them, who does the evaluation, and their behavior profile.

In the state of Georgia, autism eligibility is based on the assessment of five areas that are associated with autism. These areas include developmental delays, arrests or inconsistencies in developmental rates or sequences, delays or idiosyncratic differences in social interaction or participation, a basic deficit in use of receptive and expressive language for social purposes, unusual responses to sensory stimuli, and repetitive activities and interests. The child must show deficits in development, social interaction, and verbal and non-verbal communication to receive services under an autism eligibility in the schools. The evaluation of a child with autism includes a comprehensive psychological evaluation, education evaluation, communication evaluation, behavioral

evaluations, and developmental history. This evaluation must be conducted by a doctoral level school psychologist or a comparable professional outside of the school system.

This study will examine how the following features relate to children with autism including early diagnosis, the roles of physicians, clinicians and educational professionals in identification and assessment, research on the relationship between sociodemographic characteristics and access to health care services. The children with autism in this study were identified based on a systematic record review and scoring of *DSM-IV* criteria for autism spectrum disorders. Although all children included in the analyses for this study met the *DSM-IV* criteria for ASD, not all of the children had a previous ASD diagnosis by a qualified professional prior to inclusion in this study. In order to examine features of children who met *DSM-IV* criteria and either 1) did have a previous ASD diagnosis ("Previously Diagnosed") or 2) did not have a previous autism diagnosis ("Undiagnosed Group"), differences between the two groups will be compared on the following variables:

1) Sociodemographic variables (maternal age, maternal education, and race)
2) Age of child during the study year
3) Facility where the child was evaluated
4) Area of primary special education eligibility
5) Previous diagnoses received by the child

Hypotheses of this study include:

1) There will be more children without a previous diagnosis of autism in their record who are born to less educated mothers

2) There will be more children without a diagnosis of autism who are black

3) Children without an autism diagnosis will be younger as compared to children with a previous diagnosis.

4) Children whose records were obtained from school sources only will be more likely not to have a diagnosis of autism.

5) Children not diagnosed with autism will be more likely to have eligibility for significant developmental delay (SDD) services in the school system.

CHAPTER 2

METHODS

The data in this study were obtained from the Metropolitan Atlanta Developmental Disabilities Surveillance Project (MADDSP). MADDSP is an established developmental disabilities surveillance project that uses multiple sources in the metro Atlanta area to collect population-based data on children with developmental disabilities (Yeargin-Allsopp, Murphy, Oakley, & Sikes, 1992). The project uses medical and educational records to obtain this information. In 1998, MADDSP began collecting data on children who were between the ages of 3-10 in 1996 and who were suspected of having autism either because they were diagnosed with autism or because they had behavioral triggers associated with autism spectrum disorders in their records. 1,732 records were collected representing 1,077 children. Expert reviewers then reviewed these records and case status was determined based on a scoring system to code for the autism specific disorders in the Diagnostic and Statistical Manual of Mental Disorders 4th edition (DSM-IV) criteria. Of the 1,077 children who were reviewed 987 met the case definition for autism (Yeargin-Allsopp, Rice, Karapurkar, Doernberg, Boyle, Murphy, & Bertrand, in press).

Phase one

During phase one, the case ascertainment phase of the project, abstractors went to the multiple surveillance sites in metropolitan Atlanta and reviewed all records on children that fit the MADDSP criteria for autism abstraction. Children were abstracted

who were diagnosed as having autism based on *ICD-9* ASD codes, were suspected of having autism but not yet diagnosed, or did not have an autism diagnosis but had behavioral triggers in their record. Behavioral triggers are behaviors that children display that are signs that they may have autism. None of the children were examined directly. Detailed record abstraction was obtained for all of the children identified as a possible case. These records included information on demographics, school service data, verbatim descriptions of behaviors associated with autism, psychometric test results (intelligence, adaptive, autism), hearing and vision test results, physical/neurological findings in children with cerebral palsy, associated medical conditions, family history, and laboratory and genetic test results.

Phase two

During phase two of the review, a coding guide was developed to organize the behaviors observed in the records into *DSM-IV* criteria. Each abstracted record was reviewed by one of four autism experts (clinicians and researchers with specialized autism experience) and scored using the *DSM-IV* coding scheme. Descriptions in the record of developmental delays in the areas of social, language, or symbolic play at or before the child was three years old were scored. Behavioral regression and plateauing of skills and associated features of autism including abnormalities in the development of cognitive skills, sensory issues, and self-injurious behavior were also coded.

Children were classified as a case of autism case if their record contained indication of at least one social and either one communication or one behavioral criterion for autism (*DSM-IV* criteria for PDD-NOS). Children were labeled as a suspected case if they had behaviors that would be associated with autism, but their record did not contain

enough information to make a definitive diagnosis. In situations where a child had the number and pattern to qualify as a case but the primary reviewer questioned the relevancy of the diagnosis, a second reviewer evaluated the record. If the reviewers still questioned the case status a third review by Catherine Lord decided the case status.

To establish reliability among the expert reviewers a randomly selected set of records (20%) were independently scored by a second reviewer. Reliability was established for all reviewers using two different measures of reliability: percent agreement and a simple kappa coefficient. The raters had 95% agreement and a kappa of .47 for a case meeting the MADDSP ASD case definition for autism. This is an acceptable inter-rater reliability.

Current data analysis.

Children who met the case definition for autism based on the numbers and pattern of behaviors identified in the record by an expert reviewer but either 1) did have a previous diagnosis of autism by a qualified professional or, 2) did not have a previous diagnosis of autism by a qualified professional.

Quantitative analyses

Analyses will compare the undiagnosed group to the previously diagnosed group. The children in the undiagnosed group could have had another diagnosis (i.e., mental retardation, speech language impairment, language disorder) or they could have had no stated diagnosis. The variables that were examined in this study included, maternal age, maternal education, race, age of child, and source from which the child was abstracted. Differences between the two groups on the quantitative variables were calculated using a weighted proportion comparison analysis, which yielded a z statistic and associated p

statistic. The formula used for the analysis was p= *((n1 * P1)+(n2 * P2)) / (n1 + n2)* and z= *(P1- P2) / (SQRT((p * (1 - p))/n1) + ((p * (1 - p))/n2))*.

Information on maternal age and maternal education at the time of the child's birth was retrieved from birth certificates. Because a limited number of these children were born in Georgia, the examination of these variables was limited to children born in Georgia who had a birth certificate. Maternal age was divided into four levels: less than 20 years old, between the ages of 20-29, between the ages of 30-34, and older than 35. Maternal education was divided into four levels: less than high school, completed high school only, completed some college, and completed college or more education. Race was divided into categories of Black, White, and Other race groups. However for these analyses Black and White groups will be the focus. Children of Hispanic origin were grouped into Black and White categories; black Hispanics in the Black group and white Hispanics in the White group. Age was grouped into preschool (3-5) and school age children (6-10), and was determined by the birth date data collected from the sources where the child was evaluated.

For the purpose of these analyses sources will be categorized based on whether records were abstracted at a school source or a non-school source. Source had three levels: school-only where children were abstracted at a public school and nowhere else, non-school only where a child was abstracted at a source that was not a public school only (i.e., diagnostic clinic, private program, or private physician), and both where children were seen at both school and non-school sources. The categories of primary exceptionality are the categories of special education mentioned earlier in the paper (see

Table 2). Primary exceptionality was the primary category under which a child recived special education services.

Qualitative analyses

Other diagnoses that children in the undiagnosed category had listed on their records were obtained through additional record review. The record review was performed on those children in the undiagnosed category (n=208). Each child's evaluation records were re-reviewed to determine all diagnoses given by a qualified professional and listed in the record. As the previous diagnoses were collected, they were entered into a database created in Epi Info version 6.0. Epi Info is a software program designed to handle epidemiological data in a questionnaire format. The questionnaire designed for this study included the following variables: presence of other diagnoses (see Figure 1), type of other diagnoses, specific areas of developmental delay, other diagnostic comments made by the examiner, the number of diagnoses given, and the number of evaluations. The presence of other diagnoses in the record was defined by the presence of one of the diagnoses listed in the questionnaire (fig 1). If an examiner mentioned a diagnosis that was not on the list, it was not included as a categorical diagnosis. However, the other comments category was a text field that included diagnoses that were not included on the questionnaire and comments about a child's behavior that were suggestive of a diagnosis but not an actual diagnosis. Specific areas of developmental delay included comments made by examiners about specific areas of developmental delay that were apparent from testing done by the examiner or comparisons with same age children. The number of diagnoses was a tally of all the child's diagnoses that were listed as diagnostic categories (fig 1). If a child received the same diagnosis on multiple

evaluations it was only counted once but if the child received multiple different diagnoses they were all recorded for that child. The variable "number of evaluations" was the total number of evaluations that were included in the child's record.

Analyses included frequency counts of the items on the questionnaires and qualitative analysis of the text fields. For reliability purposes, a second coder reviewed 20% of the sample. Reliability was calculated by dividing the number of agreements by the total number of items, and an overall agreement of 98.7% was found between raters.

CHAPTER 3

RESULTS

The results of the quantitative and qualitative analyses will be presented in two sections. In the first section a summary of the comparisons made between the autism cases with a previous diagnosis of autism in their record, and autism cases without a previous diagnosis of autism in their record will be made. In the second section, the results of the record review of the subset of autism cases that had no previous diagnosis listed in their record will be presented.

208 (21%) cases of the total autism cases (987) identified by MADDSP did not have a record of a previous diagnosis of autism. 616 (62%) cases of the total autism cases had a previous diagnosis of autism in their records. The remaining cases were classified as "suspected autism." However, for the purpose of this paper this subgroup will not be further described. The frequency and percentages of the different variables are shown in Table 3.

Sociodemographic factors

There was a significant difference between the maternal age of mothers of autism cases with previous diagnosis of autism and those without a previous diagnosis of autism. There was a larger proportion of mothers in the previously undiagnosed group that were less than 20 years old ($z = -3.09$, $p < .001$) and there was a larger proportion of mothers in the previously diagnosed group that were more than 35 years old ($z = 2.10$, $p < .05$). There was a larger proportion of mothers with less than a high school education

in the previously undiagnosed group ($z = -5.14$, $p < .001$) and a larger proportion of mothers that had completed college or more education in the previously diagnosed group ($z = 3.15$, $p<.01$) (see Table 3, Figure 1). There was a significant difference in the racial composition of the two groups. There was a larger proportion of previously diagnosed children of black race ($z = 2.05$, $p < .05$) and a larger proportion of previously undiagnosed children of the white race ($z = -2.22$, $p<.05$).

Child's Age

Of cases that had a previous diagnosis of autism in their record, 33% were between the ages of 3-5 and 67% were between the ages of 6-10. Of children that did not have a previous diagnosis of autism in their record, 49% were between the ages of 3-5 and 51% were between the ages of 6-10. Comparisons between proportions in each group showed that there was a larger proportion of previously undiagnosed children in the in the 3-5 age group ($z = -7.69$, $p < .01$) and a larger proportion of previously diagnosed children in the 6-10 age groups ($z = 7.69$, $p < .01$) (see Table 3, Figure 2).

Abstraction Source and Special Education Eligibility

Comparisons between the proportions of children examined at each of the three possible sources revealed that there was a larger proportion of children previously undiagnosed that were seen in school sources only ($z = -16.93$, $p < .0001$), there was a larger proportion of previously diagnosed children that were seen at non-school sources only ($z = 2.34$, $p = <.05$), and a larger proportion of previously diagnosed children that were seen at both sources. ($z = 15.65$, $p = <.0001$) (see Table 3, Figure 3).

There were significant differences between the percentage of previously diagnosed children and previously undiagnosed children in each category of special education

except other health impaired. The magnitude of the difference between the groups was largest in the primary exceptionality significant developmental delay ($z = -11.58$, $p < .0001$) (see Table 3, Figure 4).

Record review of the previously undiagnosed group.

Frequency report

Specific diagnoses that were listed in the child's record were present in 32% of the records. There were 85 other diagnoses present in the records that represented 65 out of 208 total children in the undiagnosed group (see Table 5 and Table 6). There was an average of 1.5 evaluations per child (see Table 7). The summary diagnosis that was most frequently recorded during the record review was general developmental delay (32%). The other diagnoses (listed in descending order) were Mental Retardation (28 %), Language Disorder (9 %), Attention Deficit Hyperactivity Disorder (11%), Seizure Disorder (4%), Sensory Integration Disorder (2%), Encephelopathy (8%), Cerebral Palsy, FragileX, Learning Disability, Nonverbal Learning Disability, Obsessive Compulsive Disorder, and Sensory Impairment (all 1%) (see Table 6).

Content of text fields

The text fields in the questionnaire included specific areas of developmental delay and other possible diagnostic comments made by the examiner. Many of the evaluators made comments about specific developmental delays. These comments were consolidated and compared to identify emerging themes. Three primary themes emerged: evaluator mentions social delay (6%), evaluator mentions language/communication delay (21%), and evaluator mentions both language and social delay (6%) (see Table 8). There were also comments in the "other" category that describes the childrens' behaviors and

how these behaviors were being perceived. Several examiners mentioned that the child had behavioral and emotional problems, an “overall or generalized learning problem due to low intellectual ability”, or language problems (table 9).

CHAPTER 4

DISCUSSION

The sociodemographic and diagnostic differences between the previously diagnosed group and the previously undiagnosed group are important because they tell us about people in our society that may show significant characteristics of autism, but not be diagnosed with the disorder. A child that does not receive a proper diagnosis may be at risk for poor developmental progress and family stress. Discussion of the results of this study will focus on sociodemograpic and diagnostic differences between the groups.

Previously diagnosed group

The previously diagnosed group showed several significant differences when compared to the previously undiagnosed group. These children had a larger proportion of mothers that were older than 35 with a college education, a larger proportion of children of the Black race, a larger proportion that had been abstracted from non-school sources, and a larger proportion between the ages of 6-10.

Previously undiagnosed group

The previously undiagnosed group had a larger proportion of mothers that were less than 20 years old with less than a high school education, a larger proportion of children of the White race, a larger proportion abstracted at school sources only, a larger proportion between the ages of 3-5, and a larger proportion of children receiving services for significant developmental delay.

Sociodemographic discussion

Differences between the two groups in maternal age could be related to access to health care for young mothers. The results on maternal age should be considered with caution because they represent very few mothers in the undiagnosed group (n=9).

Important differences between the two groups in maternal education is congruent with previous research that has shown an association between maternal education and child health factors including: number of trips to the emergency room, number of doctor visits (Leventhal et al., 2000), presence of intellectual disability (Drews, Yeargin-Allsopp, Decoufle, & Murphy, 1995), and use of psychosocial services (Rosenbach, 1989). The larger proportion of mothers with college education or more in the previously diagnosed group is congruent with literature stating that the higher a mother's education the more likely they are to take their children to a doctor even if there is no problem (John et al., 1995).

Because maternal education is related to child health it should be considered when children are seen for any type of medical, psychological, or educational services. To reduce the number of children with autism that are not diagnosed, preventative measures should be taken to provide screening and follow-up assessment across families of all sociodemographic backgrounds. This could be done by including screening for developmental disabilities when the child enters school, intervention services if the child fails a developmental screener, and follow-up evaluations to measure the child's progress with the intervention. Professionals should be sensitive to the specific needs of child and family when interviewing with mothers with varying degrees of education. These modifications could include: asking questions about specific behaviors that the parent

might have observed, asking about the frequency of abnormal behaviors seen during a visit with the child, or interviewing a professional that has significant contact with the child like a teacher.

The differences between the two groups in racial composition are opposite to what was hypothesized. This finding is difficult to interpret with the literature available and will require further investigation. Current research on the relationship between race and autism has found that there are higher rates of non-isolated autism (autism with co-existing developmental disabilities) in Black children (Karapurkar & Schendel, in press). The presence of co-existing disabilities may bring a child with autism to the attention of developmental specialists earlier therefore leading to an earlier diagnosis of autism.

Age of child

The larger proportion of children between the ages of 3-5 years in the undiagnosed group would be expected from review of the literature. Seigal (1988) found the average age of diagnosis for autistic disorder was 4.5 years. The author explains that the late age at diagnosis resulted from behaviors inherent to the disability such as developmental changes and clinician's inexperience with the behaviors in autism. It is also more difficult to make a reliable diagnosis of autism in young children (Lord, 1997). As children enter elementary school two things happen: developmental differences between children with mild autism and their peers become more obvious and teachers refer children for developmental screening.

Evaluation source

Barriers to quality psychosocial services could play a role in proper diagnosis of children with autism. In this study, access to psychosocial services was measured using a

proxy variable that identified the source from which the child's records were abstracted. A larger proportion of the undiagnosed groups were abstracted at school services only. School sources are important in the identification and treatment of learning problems. Schools provide evaluations, with no monetary cost to the parents, to establish the special education eligibility of the child. Although parental consent is required for these evaluations and parental participation is encouraged, this participation is not required so a child could be assessed with no time or financial burden on the parent. These features of the schools evaluation system may allow children with families facing numerous obstacles access to proper evaluation and services. Schools however, are not required to "diagnose" children and often do not have specialists that could evaluate autism using the gold standard measures and provide a correct diagnosis for children with mild autism or children with atypical patterns of diagnostic features. Eliminating barriers to non-school sources may lead to improved mental health among the children and families that gain access to these quality psychosocial services (Leventhal, 2000). Changing the ways that services are delivered and the way that services are reimbursed could eliminate these barriers. Methods for eliminating these barriers include: increasing the flexibility of government sponsored health care plans so that all people regardless of SES have equal access to these services with no additional financial burden, additional funding to increasing the diagnostic capabilities of health departments that are accessible to low education and low-income populations, providing transportation and childcare to mothers, family support dollars that could be used to buy transportation or pay for child care, and increasing the availability of information about developmental disabilities non-

English languages and distributing this information to sites that have a multi-ethnic clientele.

Area of special education eligibility

It was found that only 9% of the undiagnosed group was not receiving special education services, which was similar to the of the diagnosed group (8%). This is positive because children may be receiving intervention services aimed at reducing problem behaviors related to autism and these interventions may improve child outcome measures. However, this finding does not show that the intervention services were appropriate. Many of the services provided for Significant Developmental Delay, which was the most frequent classification for the undiagnosed group, are only half time or involve specific therapies like speech and occupational therapy. Children with autism need intensive intervention for at least 25 hours a week, 12 months a year, according to the National Academy of Science Commission on Behavioral and Social Sciences and Education (2001) and may not get this level of intervention if they are not formally diagnosed with the disorder.

The larger proportion of children in the undiagnosed group receiving services for SDD may not be an indication of a failure to detect autism in these children but could be an artifact of the purpose of classifying a child SDD. The purpose of this category is to provide children that are showing significant developmental delays behavior driven services without giving them a definitive diagnosis. In Georgia, this category can only be used for children between the ages 3-6, and the category of services can change no later than the end of the school year that they turn 6 years old. Therefore, it would follow that

a group that has more children between the ages of 3-5 would have more children receiving SDD services.

The larger proportion of children in the undiagnosed group that had speech and language services as their primary exceptionality may reflect evaluator's difficulty in differentiating children with autism from children with language delay. Differential diagnosis between speech language pathologies and autism is difficult because of overlapping behaviors (Lord, 1997). Communication problems are often apparent in children with autism and these children may receive speech and language evaluations more often than a full diagnostic assessment that would assess other features of autism. Training for speech and language pathologists to monitor for red flags for autism may help identify these children. The larger proportion of children in the undiagnosed group that were receiving services for behavioral and emotional disorders may represent difficulties in distinguishing internalizing and externalizing behaviors from autism. Nylander and Gillberg (2001) reported that the majority of the patients in mental hospitals that were diagnosed with autism after a screener was administered were being treated for psychosis and personality disorders. Diagnosing autism in people with psychosis and personality disorders is of great importance in high functioning children with ASD's like Asperger's disorder because there is high comorbidity with psychotic disorders (Klin &Volkmar, 1996). Education for evaluators about the co-occurrence of emotional and behavioral disorders in children with ASD may increase their correct diagnosis.

Because a large percentage of these children with a previous diagnosis had a primary eligibility of autism, we can assume that they were in schools with autism

programs. In a school with an autism program there are teachers in those classrooms that have a good understanding of what autism looks like and can be called on to observe children that may be showing behavior problems not understood by other people in the school.

The diagnostic requirements for autism eligibility in the school may work to exclude children with types of ASD's that are more difficult to diagnose if the examiner does not have a large base of experience with ASD's. Children with Asperger's often show no verbal delays and may seek the attention of others. These behaviors make these high functioning children difficult to place in an eligibility category that requires verbal delay although they may benefit from these services. Examiners in the schools would benefit from training on the full spectrum of autism and how to diagnose autism when there are few signs of communication problems.

Previous Diagnosis

A qualitative record review revealed three themes representing diagnostic complications and errors among the children in the undiagnosed group. These themes included, among others, complicated medical problems, age complications, and evaluation complications. The complicated medical problems reported in records included: complications at birth, Fragile X, and Congenital Heart Defects. Age was a complicating factor, because in 1996 some children were between the ages of (3-4) and had come into the system too recently to receive the full battery of evaluations necessary to receive a diagnosis of autism. Evaluation complications represented a mismatch between the skills or goals of the evaluator (eligibility for services not diagnosis) and the child's disability. Young children with autism may be less likely to be diagnosed with

autism because of the effect of medical conditions and age on the reliability and validity of testing and the length of time that is required to make a diagnosis of autism (Lord, 1997; Seigal et al., 1988). The organization and funding in the public school systems may also affect the role of the schools in identifying children with autism. The best measures used to diagnose autism require days of training to establish reliability and validity. Because of the cost of these measures, many school systems may not be able to afford these tools. In the schools, eligibility reflects more than classification of a child's behavior it reflects classroom space and staff available for the treatment of children with special needs. Because of these limitations, children who have behavior problems or mental retardation and autism may be classified as one of these other disorders so that they do not require as much testing, or do not require placement in services that are not available in the school system.

Strengths and weaknesses

One strength of this study is that the data are from an ongoing population based developmental disabilities surveillance program. Few studies on autism have encompassed such a large sample. Also, one set of criteria (*DSM-IV*) was applied to all records by the same group of clinicians. Another strength of this study is the sociodemographic diversity of the sample that results from the diversity in a major metropolitan area in the southeast region of the United States. The multiple source ascertainment procedures used by MADDSP have allowed this study to look at both clinical non-school sources and school sources. Because most studies of autism have derived samples from clinical populations, they may not have included many of the children with the socidemographic factors that distinguish the previously diagnosed and

previously undiagnosed groups. Because children were reviewed that did not have a previous diagnosis of autism this study has been able to examine a population that may never have been identified and brought into the literature.

The most obvious weakness of this study is that none of these children were re-evaluated directly by the same set of clinicians. Therefore, although the same scoring criteria were applied to all cases, it was based on the behavioral data given by other professional observations that could have had wide variability in their experiences, opinions, and education. Another weakness of this study is the use of independent percentage comparisons on each level of each variable. This statistical method does adjust for co-variance between the variables. Another weakness of this study is that some of the variables that were used may not be valid proxies of the concepts that are included in this study. Specifically, primary exceptionality may not reflect diagnosis, and source from which the data was abstracted may not reflect accessibility to health care.

Future research in this area should include variables like family income, severity of autism, all sources where a child was seen, and information on both the mother and the father. Data should be analyzed using multivariate analyses. Follow up research should be conducted on the children in the undiagnosed groups to validate their case status. Future research should also compare the characteristics of children previously suspected of having autism with the previously undiagnosed and diagnosed groups. Further research on the differences between the evaluation and diagnostic processes in school and non-school sources, might also make the ways that children are identified across systems more transparent.

APPENDICES

APPENDIX A- TABLES

Table 1
Diagnostic Criteria Used in Prevalence Studies of Autism

Diagnostic System	**Criteria**
Kanner's criteria (Kanner, 1943)	1) lack of affective contact 2) repetitive behavior
Rutter's criteria (Rutter, 1978)	1) impaired social development 2) delayed and deviant language 3) insistence on sameness 4) onset before 30 months
DSM-III	1) lack of responsiveness to others 2) language absence or abnormalities 3) resistance to change or attachment to objects 4) the absence of schizophrenic features 5) onset before 30 months
DSM-III-R	1) impairment in social interaction 2) impairment in verbal and non-verbal communication 3) markedly restricted repertoire of activities and interest 4) at least 8 of the 16 items listed
DSM-IV	Same as DSM-II-R except the age of onset has to be before age 3 years and the disorder is not due to Rett's or Childhood Disinigrative Disorder.

Table 2.
The Definitions of Different Special Education Categories.

Eligibility category	Category Definition	Assessment procedure
Autism	Deficits in three of five areas 1) developmental rates and sequences 2) social interaction and participation 3) communication 4)sensory processing 5) repertoire of activities and interests	1) Psychological evaluation 2) Educational evaluation 3) Communication evaluation 4) Behavioral evaluation 5) Developmental history
Deaf/hard of hearing	Deaf: absence of enough measurable hearing that the primary sensory input for communication may be other than the auditory channel Hard of Hearing: The absence of enough measurable hearing that that the ability to communicate is adversely affected.	1) audiological evaluation 2) otological evaluation 3) educational evaluation
Emotional and behavioral disorder	Student who exhibits emotionally based characteristics to the degree that it interferes with educational performance 1)unable to build and maintain satisfactory interpersonal relationships 2) inability to learn that is not explained by other factors 3) consistent or chronic inappropriate type of behavior or feelings under normal conditions 4) pervasive mood of unhappiness or depression 5) development of physical symptoms due to personal or school problems	1) Documentation of prior modifications of a regular program 2) Psychological evaluation 3) Educational evaluation 4) Long term behavioral reports 5) Appropriate social history 6) Documentation of the duration, frequency, and intensity of one or more of the characteristics of the disorder
Intellectual disability	Significantly sub average general intellectual functioning which exists concurrently with deficits in adaptive behavior both of which effect the educational performance of the child	1) Psychological evaluation 2) Educational evaluation
Orthopedic impairment	Severe orthopedic impairments that effect the child's educational performance to the point that they require special education.	1) Current medical assessment 2) Educational assessment
Other health impaired	Having limited strength, vitality, or alertness including a heightened alertness to environmental stimuli, that results in limited alertness to the point that educational performance is affected	1) medical evaluation 2) educational evaluation
Significant developmental delay	Children between the ages of 3-5 that show a developmental delay in adaptive behavior, cognition, communication, motor development, or social	1) psychological evaluation 2) educational evaluations

	development to the extent that, if not provided with special education services educational performance may be affected.	
Specific learning disability	A disorder in one or more of the basic psychological processes involved in understanding or using language, spoken or written, that may manifest itself in imperfect ability to listen, think, speak, read, write, spell or do mathematical calculations	1) psychological evaluation 2) educational evaluations
Speech-language impairment	A communication skill which differs so signifigantly in manner or content from that of peers that it is apparent, disrupts communication or affects emotional, social, intellectual or educational growth.	1) Hearing and vision screening 2) Speech assessment 3) Functional communication assessment
Traumatic brain injury	An injury to the brain caused by external forces that results in a disability or psychosocial impairment that adversely affects the students educational preference.	1) medical report 2) psychological evaluation 3) summery of pre-injury performance

Table 3:
MADDSP Cases: Variables to be compared by their previous ASD diagnosis status

Characteristic	**Previously Diagnosed (n=616)**		**Previously Undiagnosed (n=208)**	
	n	%†	n	%†
Maternal age‡‡				
<20***	14	3	9	6
20-29	206	51	75	52
30-34	117	29	40	28
>35*	70	17	19	13
Total	407		143	
Maternal education‡‡				
<12***	29	7	21	15
12	116	29	37	26
13-15	109	27	42	29
>=16**	153	38	43	30
Total	407		143	
Race				
Black*	229	37	68	33
White*	364	59	134	64
Total	616		208	

	Previous Diagnosis		No Previous Diagnosis	
Characteristic	n	%†	n	%†
Age of child				
3-5**	204	33	102	49
6-10**	412	67	106	51
Total	616		208	
	n	%	n	%
Source				
Both***	404	66	68	33
School only***	179	29	133	64
Non-school* only	33	5	7	3
Total	616		208	
Primary exceptionality				
Mild ID	25	5	23	11
Moderate ID	15	3	9	4
Severe ID	11	2	3	1
Profound ID	5	1	4	2
Behavior disorder	29	5	27	13
Learning disability	7	1	8	4
Other health impaired	23	4	11	5
Speech and language	38	7	23	11
Significant developmental delay***	91	17	78	38
Autism***	291	53	0	0
Total	616		208	

† Reported as proportions within each group

‡‡ Information was available only on a subset of children (n=407 previously diagnosed) (n=143 previously undiagnosed)

* p<= .05

** p<= .01

*** p<=.001

Table 4:
The Possible Other Diagnoses that will be Included in the Database.

Anxiety Disorder
Attention Deficit Hyperactivity Disorder
Bipolar Disorder, Manic-Depression
Brain Injury
Cerebral Palsy
Childhood Disintegrative Disorder or Rett's Disorder
Conduct Disorder
Depression
Developmental Delay, Significant Developmental Delay (includes Receptive, Expressive, or Mixed Language Disorder)
Down syndrome
Emotional Disorder
Encephalopathy
Fragile X
Language/Communication Disorder
Learning Disability
Mental Retardation/Cognitive Impairment
Mutism
Obsessive-Compulsive Disorder
Oppositional Defiant Disorder
Personality Disorder
Psychosis
Reactive-Attachment Disorder
Schizophrenia and related disorders
Seizure Disorder/Epilepsy
Tourette's Disorder, Tic Disorder
Tuberous Sclerosis
Other

Table 5.
The Number of Children in the Previously Undiagnosed Group that had One or More Other Diagnoses Present.

Other diagnosis?	**Frequency**	**%**
Yes	65	32
No	141	68
Total	206	100

Table 6.
The Frequency of Different Diagnoses Given by a Qualified Professional in the Undiagnosed Group.

Other diagnosis	**Frequency**	**%**
ADHD	9	11
Cerebral Palsy	1	1
General developmental delay	27	32
Encephalopathy	7	8
Fragile x	1	1
Language disorder	8	9
Mental retardation	24	28
Nonverbal learning disability	1	1
Obsessive compulsive d/o	1	1
Seizure d/o	3	4
Sensory impairment	1	1
Sensory integration d/o	2	2
total	85	

Table 7.
The Number of Evaluations in the Undiagnosed Group

Number of Evaluations	**Frequency**	**%**
1	130	63
2	47	23
3	19	9
4	7	3
5	2	.9
Total	206	

Table 8.
The Content of the Developmental Delay Category

Content of the specific developmental delay category	**Frequency**	**%**
Mention of both language and social delay	13	6
Mention of language/communication delay	43	21
Mention of social delay	11	5

Table 9.
The Content of the Other Category

Behavior	**Frequency (n)**	**%**
Behavioral or emotional problems	16	8
Generalized learning problem due to low intellectual functioning	13	6
Language problems	11	5
ADD/ADHD tendencies	9	4
Social problems	6	3
Communication problems	5	2
Adaptive behavior	4	2

APPENDIX B-FIGURES

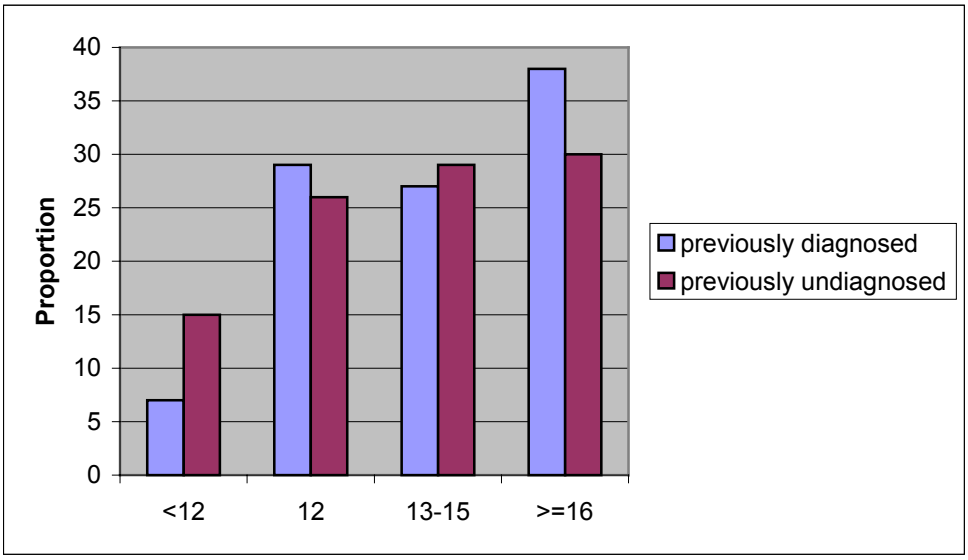

Figure 1. Group Differences in Level of maternal education

Figure 2. Group Differences in Age

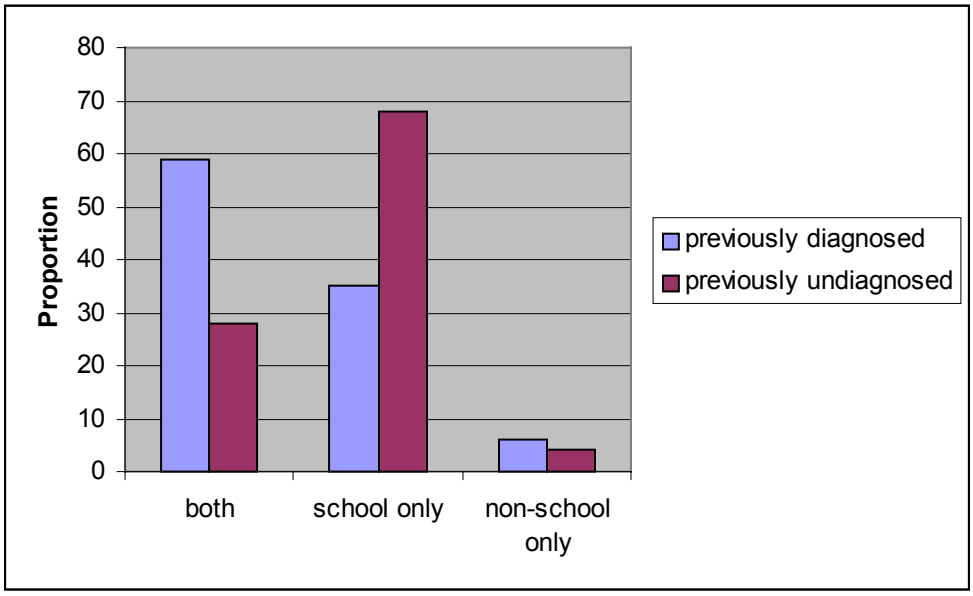

Figure 3. Group Differences in Source of Abstraction

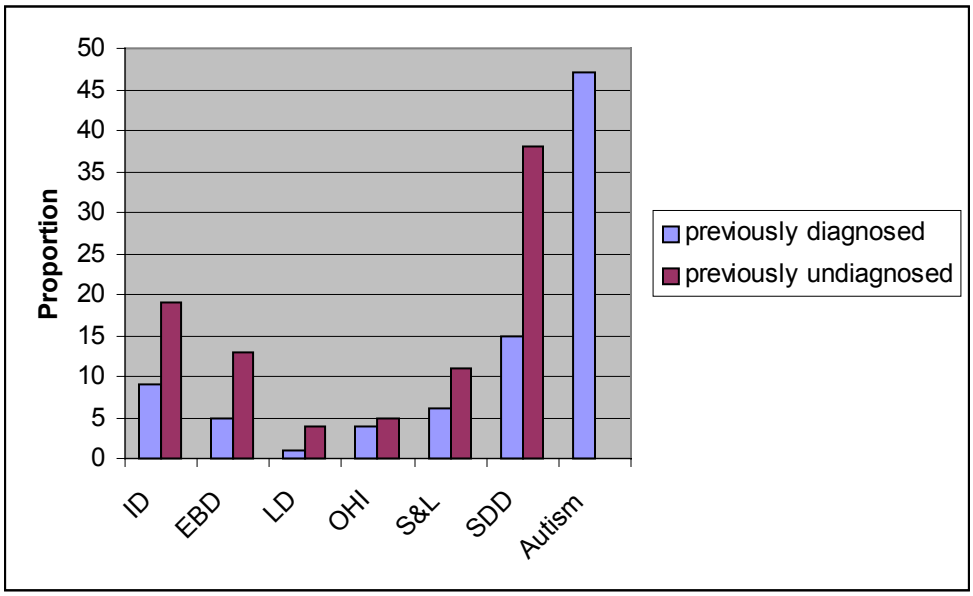

Figure 4. Group Differences in Primary Exceptionality

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