Prevalence of Autism in Brick Township, New Jersey, 1998: Community Report

Centers for Disease Control and Prevention
April 2000

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Executive Summary

Background

A citizen's group in Brick Township, New Jersey contacted the New Jersey Department of Health and Senior Services (DHSS) in late 1997 with concerns about an apparently larger than expected number of children with autism in Brick Township. Because of the complexity of the disorder and the citizens' concern that environmental factors might play a role, the New Jersey DHSS, U.S. Senator Robert Torricelli, and U.S. Representative Christopher Smith contacted the Centers for Disease Control and Prevention (CDC) and the Agency for Toxic Substances and Disease Registry (ATSDR) for assistance. In response, a four-part plan was developed, including a prevalence investigation, a literature review of environmental factors associated with autism, an investigation of environmental pathways for human exposure in the community, and community education and involvement activities. This report presents the results of the prevalence investigation.

Methods

The objective of the prevalence investigation was to determine the prevalence rate of autism in children aged 3-10 years who were living in Brick Township in 1998. Investigators used a two-phase approach. Phase I involved identifying all children whose condition might meet the case definition for autism by reviewing records at schools, service providers (physicians or programs for children with autism) and from names provided by the citizen's group. Phase II was to verify case status through an examination by a developmental pediatrician, using the Autism Diagnostic Observation Schedule-G (a scientifically well-established tool for diagnosing autism) in addition to standard clinical procedures. Autism included the spectrum of disorders defined by the American Psychiatric Associations's Diagnostic and Statistical Manual--Fourth Revision (DSM-IV), i.e., autistic disorder, Asperger's disorder, and pervasive developmental disorder--not otherwise specified (PDD-NOS). In order to determine the prevalence rate, it was necessary to estimate the number of children aged 3-10 years in Brick Township in 1998.

Results

Phase I of the investigation identified 75 children with possible autism. In Phase II, 60 children were found to meet the DSM-IV criteria for an autism spectrum disorder (ASD). The prevalence rate of ASD was 6.7 cases per 1,000 children (95% CI- 5.1-8.7). For the subset of 36 children whose condition met the diagnosis for autistic disorder, the prevalence was 4.0 cases per 1,000 children (95% CI = 2.8-5.6). The male-to-female prevalence ratios were 2.2 and 3.7 for autistic disorder and PDD-NOS, respectively. Sixty-three percent of the children with autistic disorder had an IQ score of less than or equal to 70 (i.e., mental retardation). Of children with a known birth residence, 64% were born in Brick Township. Seven children were reported to have a brother or sister who also had an ASD.

Conclusions

The rate of autistic disorder and ASD in Brick Township were high relative to previously published studies from other countries. There are no recent prevalence studies of autism in the United States. However, there are a few very recent studies from other countries that have yielded similar rates. These studies, like the Brick Township investigation, tended to use relatively intense case-finding methods.

The well described epidemiologic characteristics of children with ASD in Brick Township-- the predominance in males and the high proportion of children with IQ of 70 or less -- were observed in the Brick Township population, which provides support for the appropriateness of our study methods.

Whether the Brick Township rates are higher than expected is difficult to answer because of the uncertainty about the true rate of autism. Recent higher prevalence rates found in other countries along with the increase in the number of children seen by service providers in the United States, is believed to be due in part to the broadening of the diagnostic criteria and improved recognition.

To help with the interpretation of the rate of autism in Brick Township, and rates in other communities, we need comparable data on the prevalence of autism in several large and diverse populations in the United States. Studies examining the role of genetic, infectious, immunologic, and environmental factors in the occurrence of autism are also needed.

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Background

Brick Township, New Jersey, a town of about 77,000 residents, is located approximately 60 miles north of Atlantic City, just a few minutes from the Atlantic coast. In late 1997, a citizens' group in Brick Township, Parents of Special Services and Education (POSSE) contacted the New Jersey Department of Health and Senior Services (DHSS) with the results of a survey they had conducted on the number of children in their community with autism. The results of this survey suggested that the rate of autism among Brick Township children could be several times higher than expected based on prevalence rates for the disorder. In early 1998, the Centers for Disease Control and Prevention (CDC) and the Agency for Toxic Substances and Disease Registry (ATSDR) were contacted by the New Jersey DHSS, U.S. Senator Robert Torricelli, and Representative Christopher Smith about the possibility of federal assistance in addressing the concerns of the citizens of Brick Township. CDC assistance was requested because of the complexity of investigating a disorder such as autism, in which the diagnosis is based solely on the behavioral characteristics of the child, and CDC was developing epidemiologic methods to address the unique challenges of autism. ATSDR's expertise was requested because of a concern by the community that the apparent increase in autism might be caused by environmental factors.

In response to the requests for federal assistance, a four-part Health Action Plan for Brick Township was developed which included: (1) a prevalence investigation of autism; (2) a review of the literature on the association between chemical contaminants and autism; (3) an investigation of environmental pathways for human exposure in Brick Township; and (4) community involvement and health education activities. This report presents the results of the Brick Township autism prevalence component.

Methods

The population for the prevalence investigation was children aged 3 through 10 years whose parents resided in Brick Township, New Jersey, at any time during 1998. The age range was chosen to be analogous with the ages of children identified in CDC's Atlanta-based surveillance program for autism and other developmental disabilities, the only other current U.S. population-based study of autism.

Children with autism in Brick Township were identified using a two-phase process. In *Phase 1,* all children who met the age, study year, and parental residence requirements with possible autism were identified through a review of school, medical, and other source records. In *Phase 2,* clinicians with training and experience in diagnosing autism confirmed the diagnosis in children identified through *Phase* 1.

Case definition: The case definition included children with an autism spectrum disorder (ASD). This includes the diagnoses of autistic disorder, pervasive developmental disorder--not otherwise specified (PDD-NOS), and Asperger's disorder, based on the American Psychiatric Association's Diagnostic and Statistical Manual--Fourth Edition (DSM-IV) criteria. The case definition did not include children with childhood disintegrative disorder or Rett Syndrome. (See Appendix for DSM-IV criteria.)

Phase 1--Identification of children in Brick Township with a possible ASD.

Three sources were used to identify children with a possible ASD: 1) school records maintained by Brick Township Schools, Department of Special Services; 2) records of private physicians (i.e.,

neurodevelopmental pediatricians and pediatric neurologists) and private schools or programs that specialize in diagnosing or treating ASD in children; and 3) lists of children with a possible ASD maintained by POSSE and children whose parents contacted CDC directly .

To identify children whose condition might meet the prevalence case definition from special education records in the Brick Township schools, a developmental psychologist reviewed records of all children who received special education services in 1998. This review included records of children who were receiving services in private schools (for whom the services were paid by the Brick Township school system) and children who were evaluated for services but did not meet eligibility requirements for services. Children were identified as possible cases if their special education classification was an ASD, their record described behaviors consistent with diagnostic criteria for ASD, or another indication that an ASD may be present (i.e., a sibling with the disorder).

To identify children with ASD from private clinicians and private schools or other programs that provide services to children with autism, a list of such sources was developed through input from parents, school administrators, parent organizations (i.e., POSSE and the Center for Outreach Services for the Autism Community), the Ocean County Health Department, and area phone books. Fifteen private schools, four psychiatric facilities that provide inpatient and/or outpatient services for children with autism and other psychiatric disorders, three child psychiatrists, four pediatric neurology practices, and one general pediatrician were identified as possible sources. CDC investigators contacted these potential sources by telephone to determine whether they provided services to any children from Brick Township. Several schools provided services for Brick Township children with autism, however; these children already had been identified from the special education files maintained by the Brick Township schools. The psychiatric facilities all reported that in 1998 they served no children with autism from Brick Township. Of the clinicians, three pediatric neurologists were identified who provided diagnosis and treatment to children from Brick Township in 1998 and who allowed access to their records. The fourth pediatric neurologist reported having seen no children with an ASD from Brick Township. A review of the files from the general pediatrician indicated that we had already identified all children with autism in that practice. We were unable to obtain any information from the three child psychiatrists. Although it is unknown whether additional children would have been identified from the three child psychiatrists, only one of these clinicians was named in the record review at the school and other sources.

The final source for case identification included the lists of children with possible autism maintained by POSSE (after permission was obtained from the parents to forward their names to CDC) and parents who contacted CDC directly after learning of the investigation.

For each child identified as a possible case-child from the schools, physician offices, and the parent lists or inquiries, a team of two CDC research assistants (who specialized in abstracting psychological and medical reports for children with developmental disabilities) abstracted information from the records onto an abstract form developed by CDC investigators for use in its Atlanta-based autism surveillance program. Information abstracted from the records included demographic factors, descriptions of behaviors consistent with the DSM-IV diagnostic criteria for an ASD, standardized testing results (e.g., IQ testing), special education eligibility/classification, and selected medical tests and procedures (e.g., genetic testing results, metabolic screening results).

Phase 2 -- Clinical assessment for autism.

Families of children who were identified in *Phase 1* were invited to participate in a clinical assessment. For logistical reasons, the six children who were identified from physician offices only were not invited to participate in the clinical assessment. The purpose of the clinical assessment was to use a standardized instrument in applying the DSM-IV criteria for ASD in children identified in *Phase 1*. The clinical examination also afforded the opportunity to obtain consistent demographic and medical history information. All clinical assessments were conducted at the Ocean County Health Department after written informed consent was obtained from parents of all participating children.

The clinical evaluation was conducted by a developmental pediatrician with extensive experience in diagnosing and treating children with ASD. The clinical evaluation included a medical, developmental, and behavioral history; a standard physical and neurologic examination; and front and side view photographs, that were subsequently evaluated by a geneticist. In addition to these standard clinical procedures, the Autism Diagnostic Observation Schedule-G (ADOS-G) was administered. The ADOS-G is a semistructured observational assessment that includes activities to evaluate the child's functioning in the critical areas of social interactions, communication, and repetitive or restrictive behaviors. The ADOS-G allows for DSM-IV diagnoses within the autism spectrum, with threshold scores for autistic disorder (Lord, 1998; Lord & Risi, 1998; Lord et al., 1989). The developmental pediatrician received special training in the administration of the ADOS-G and the reliability of her diagnosis was monitored in accordance with recommended guidelines for this measure.

In addition to the clinical evaluation by the developmental pediatrician, a battery of tests was administered by a developmental psychologist to assess the intellectual, language, spatial-cognitive, and adaptive functioning of each child. Three instruments were used: the Differential Abilities Scale (a test of general intelligence, Elliott, 1990); the Developmental Test of Visual-Motor Integration (which assesses spatial-cognitive ability, Berry, 1997); and the Vineland Adaptive Behavior Scales (which measures application of cognitive ability to functioning in everyday life, Sparrow et al., 1984). Each of the tests is standardized for administration and scored to a mean of 100 and standard deviation of 15. Scores below 70 (or two standard deviations below the mean) indicate significant delay or impairment.

Case Status. Case status was determined using all information for each child. For the children who participated in the clinical examination, the diagnosis of ASD was determined primarily from the ADOS-G results, although the developmental history of the child was also considered. However, history and functioning information altered the final case status based on the ADOS-G results in only a few instances. For all other children identified as possible case-children (i.e., children who were invited but did not participate in the clinical assessment phase and children identified from physician offices only), the clinicians determined case status on the basis of a review of all the abstracted diagnostic information for each child. Behaviors described in these abstracted records that corresponded to each of the DSM-IV criteria for autistic disorder were recorded by the clinicians onto an abstract form. Following DSM-IV criteria, the number and pattern of behaviors were used to determine whether the child was within the autism spectrum and whether the child's disorder met the full diagnostic criteria for autistic disorder.

Calculation of Prevalence Rates The prevalence rates of all ASD (autistic disorder, PDD-NOS, and Asperger's disorder), autistic disorder alone, and other spectrum disorders (i.e., PDD-NOS and Asperger's disorder combined) were calculated for children aged 3 years through 10 years, who resided in Brick Township at any time during 1998. The numerator of the rate is the number of children identified by the clinical exam or clinical record review (when exams were not done) as meeting the case definition for one of these conditions. The denominator is the estimated number of children aged 3 through10 years whose parents resided in Brick Township in 1998.

Because the exact number of 3- to10- year old children living in Brick Township in 1998 was not available, we estimated the denominator by adjusting the 1990 census count of 7,117 by a 25% inflation factor. This inflation factor was equivalent to the increase observed in the Brick Township student population for grades K through 5 in the school years 1989-90 and 1998-99, which were provided by the Brick Township Public Schools. Using this inflation factor, the estimated number of children aged 3 - 10 years in Brick Township in 1998 was 8,896 (4,364 girls and 4,532 boys).

Statistical precision of the prevalence rates were assessed by computing 95% confidence intervals, which indicate that 95% of the time the interval will include the true rate. Confidence intervals were used to compare prevalence rates within Brick Township, such as between younger and older children, and to compare the prevalence in Brick Township with that found in other studies. Confidence intervals that do not overlap provide guidance that the rates are statistically different from one another.

For the most part, the analyses include information about all children identified with an ASD in Brick Township, with the sample restricted for a few analyses only to children who participated in the *Phase 2* clinical assessment. Findings are presented for all children within the autism spectrum as well as separately for children whose disorder met the diagnostic criteria for autistic disorder and for children who had the other spectrum disorders (PDD-NOS/Asperger's disorder).

Results

Seventy-five children were identified as possible case-children in *Phase 1* of the investigation (Table 1). Most (83%) were identified at more than one source. Of the 75 possible case-children, 53 participated in the clinical examination, and 22 were evaluated solely on the basis of diagnostic information included in school and physician records. Sixty of the 75 potential case-children met the DSM-IV criteria for an ASD; 36 of these children met the criteria for autistic disorder. Fifteen children identified as possible case-children in *Phase 1* did not meet the ASD diagnostic criteria; these children had a number of other developmental disorders, such as attention deficit hyperactivity disorder, mental retardation, or a speech disorder. The following results are based on the 60 children whose conditions met the DSM-IV criteria for an ASD.

The overall and age-specific prevalence rates in Brick Township for autistic disorder, other spectrum disorders (PDD-NOS/Asperger's disorder), and all ASDs combined are presented in Table 2. Age-specific rates were based on the child's attained age in 1998. The overall rate of autistic disorder is 4.0 cases per 1,000 children aged 3-10 years, with a 95% confidence interval (CI) ranging from 2.8 to 5.6. The overall rate for children meeting the criteria for other spectrum disorders was 2.7 (95% CI = 1.7-4.0). Finally, the overall rate of ASD was 6.7 cases per 1,000 children aged 3-10 years (95% CI = 5.1-8.7). Age-specific prevalence rates of ASD or autistic disorder in children 3-5 years old did not differ significantly from those among children 6-10 years in 1998, although the tendency was for lower rates prevailing among the older aged children.

Forty-four (73%) of the 60 children with ASD were boys (Table 3). The male-to-female prevalence rate ratio was higher for children with PDD-NOS/Asperger's disorder than for children with autistic disorder, 3.7 and 2.2, respectively.

The racial/ethnic distribution of children with ASD was 89% white non-Hispanic, 4% Hispanic, 4% other races, and 3% unknown. This distribution is comparable to Brick Township--94% white non-Hispanic, 4% Hispanic, and 2% other races. Of the 60 children with ASD, maternal residence at time of the child's birth was obtained from school or other sources (e.g., birth certificates) for 56 (93%) of the children. Of the 56 children with known birth residence, 36 (64%) were born in Brick Township, and 20 (36%) had a maternal residence other than Brick. One child with ASD, born outside Brick Township, was adopted.

In addition to the 43 case-children who participated in the clinical exam, IQ information was available for two of the 17 children with only record information, and these children are included in the IQ analysis. The mean IQ score for children with ASD was 72 (range 45 to 118); 21 (47%) children had IQ scores less than or equal to 70. Of children who met the diagnostic criteria for autistic disorder, 50% had an IQ score of less than or equal to 70, and 40% of those with PDD-NOS/Asperger's disorder fell in this range (Table 4). Four children with autistic disorder could not complete the IQ testing because of limited language ability and/or cooperation. All four of these children were considered by the developmental psychologist to be functioning in the moderate to severe range of mental retardation; the corresponding Vineland standard scores for each child was less than 50, indicating moderate to severe deficits in skills of daily living. Including these four children in the less than or equal to 70 IQ group would result in 63% of the children with autistic disorder functioning in the range of mental retardation.

Parents were asked during the clinical assessment whether their child had experienced any loss of acquired skills before the diagnosis of ASD. Ten of the 43 children who participated in the exams, all in

the autistic disorder category, were reported by their parents to have lost skills. The earliest age of skill loss was reported as 12 months for four children, 13 months for one child, 15 months for two children, and 18 months for three children. For the 17 children with record information only, no information in their medical or school records indicated a loss of skills.

Seven children from four families were reported by their parents as having a sibling with an ASD (Table 5). For three of these sibling pairs, both children met the age criteria to be included in the prevalence investigation. There were a total of 81 siblings in the investigation, which yields a sibling rate of ASD of 4.9%. In addition, six children were reported to have one or more siblings with a developmental disability other than an ASD, primarily attention deficit hyperactivity disorder or speech/language disorders.

Five (8.6%) of the 60 children had specific medical conditions that have been found in other studies to be associated with autism. These conditions were seizure disorder (two children), fragile X syndrome (two children), and a genetic translocation (one child). A clinical geneticist at CDC reviewed photographs and videotapes the facial features of 43 children who participated in the clinical evaluation and indicated that none had a major, recognizable syndrome. A few children had several dysmorphic features, but there was no common facial appearance.

Discussion

The rate of autistic disorder in Brick Township was 4.0 per 1,000 children. The rate for the spectrum of autism disorders obtained in this investigation was 6.7 per 1,000 children. These rates are higher than previously published rates. However, there is much controversy about the actual rate of autism. Considerable debate has focused on the actual prevalence of autism and whether the prevalence has increased during the past 20-30 years (Fombonne, 1996; 1999; Gillberg & Wing, 1999). Nearly all recent studies (Table 6) suggest that the prevalence of autism is considerably higher than the rates of 0.4 to 0.5 per 1,000 that were originally described. These early rates were based on narrowly defined criteria for autism that included two essential features--a profound lack of affective contact and elaborate repetitive and ritualistic behaviors (Kanner & Eisenberg, 1956). More recent diagnostic criteria for autism, based on the DSM-IV (1984) or the *International Classification of Diseases Tenth Revision* (ICD-10, 1992), are considerably broader incorporating the clinical recognition that the hallmark features of autism–impaired social interactions, inability to communicate, and repetitive or restrictive behaviors–can occur in a wide range of severity levels with several different manifestations (Wing, 1993; Filipek, et al., 1999). Recent reviews of the prevalence of autism (Fombonne, 1999; Gillberg & Wing, 1999) suggest that a conservative estimate of the prevalence of autistic disorder from studies published in the 1990's is about 1 per 1,000 children. For the entire spectrum of autistic disorders, the rate of 2 per 1,000 that was obtained by Wing and Gould (1979) is cited most often. However, a few recent studies have shown rates that are considerably higher than the above estimates. Specifically, studies conducted in Japan and Sweden showed rates of autism ranging from 2.1 to 6.0 per 1,000 children (Honda et al, 1996; Arvidsson et al., 1997; Kadesjo and Gillberg, 1999). Although each of these studies included relatively small populations, which would have facilitated more intensive case finding methods, the small sample sizes also resulted in statistically unstable prevalence rates as reflected by wide confidence intervals. However, a study recently completed in the United Kingdom, with a considerably larger population, reported a provisional rate of 3.1 per 1,000 children for autistic disorder and 5.8 per 1,000 children for ASD (Baird et al., in press). One reason for the higher rates in these studies may be their more intensive case-finding methods that included screening the entire population. As discussed below, intense case finding activities may have contributed to the high rate in Brick Township.

Another important point to consider when interpreting the rate found in Brick Township is the lack of U.S. data on the prevalence of autism, although there is no reason to believe that the rate in U.S. populations should differ appreciably from other population groups. The data used by Gillberg and Wing (1979) to derive their estimate of 1 per 1,000 for the prevalence of autism is based on studies conducted outside of the United States. The two U.S. studies that satisfied the criteria to be included in the review--population-based screening followed by a clinical evaluation--obtained rates of 0.3 per 1,000 (Burd et al.,

1987; Ritvo, et al, 1989) and are considered outliers by most investigators (Gillberg & Wing, 1999). The low rates in these U.S. studies probably result from their exclusive reliance on referred cases from sources that provided services to children with autism, rather than actively reviewing all potential source records as in the Brick Township investigation.

Other U.S. data sources seem to support the idea that the prevalence of autism is higher than previously thought, although how much higher is still uncertain. A recent report released by the California Department of Developmental Services (DDS) showed a large increase from 1987 to 1998 in the number of children with autism for whom the DDS provided services. We estimated a prevalence rate from the California DDS data of 1.5 per 1,000 4-9 year old children (95% CI=1.45-1.54) in 1998 by using the number of children aged 4-9 years receiving DDS services for autism in 1998 as the numerator and the U.S. census estimate of the number of children in this age range living in California in 1998 as the denominator. This rate is probably an underestimate because this service system is unlikely to identify all children with autism. CDC has recently completed data collection for a large prevalence study in metropolitan Atlanta. Although case review and data analysis are ongoing, provisional rates of autistic disorder based on the number of cases reviewed (40% of total), and assuming a similar rate of case confirmation for the remainder, range from 2 to 3 per 1,000 3- to 10-year-old children. The combination of the Atlanta and California data suggest that the rate of autistic disorder in the United States is substantially higher than the 1 per 1,000 estimate of Gillberg and Wing (1999), although how much higher and how the rates vary across different subpopulations is yet to be determined.

Another data source that might add some perspective to the Brick Township rates is the New Jersey special education data for autism. The percentage of children provided special education services by Brick Township was not unusual compared to other towns in New Jersey during 1997. In the annual reporting for federal funding under the Individuals with Disabilities Education Act, there were over 100 towns in New Jersey that reported a higher percentage of children in autism special education classes than reported in Brick Township (Factor-Litvak, personal communication). However, the special education data have to be viewed with caution because school placement is based on the educational needs of the child rather than exclusively on underlying diagnosis, and classification practices may vary among school systems. For example, in Brick Township, only 50% of children with an ASD and 66% of those with autistic disorder had autism listed as their special education designation for services.

Differences in study methods may account for much of the variability in autism prevalence rates (Fombonne, 1996; 1999; Gillberg & Wing, 1999; Wing, 1993; Bryson & Smith, 1998). We mentioned previously that other studies with higher rates tended to have more intense case finding methods. In Brick Township, a number of factors contributed to the intensity of case finding. First, the relatively small size of the target population allowed CDC investigators, parents, and professionals in the community to be especially thorough in identifying and reviewing potential case sources. Second, the local school system was fully cooperative with investigators, which facilitated the identification of all children receiving special education services, including newly referred children. Third, the well-organized citizen groups resulted in an acute awareness of the features of autism in the community among both parents and professional groups. Finally, the intense media coverage that followed the initial report of a possibly large number of children with autism in Brick Township undoubtedly led to a greater awareness of the condition by parents and professionals.

We found 1.5 times more children with autistic disorder than with other ASDs. A recent review suggested just the opposite–a higher prevalence of other spectrum disorders than autistic disorder (Fombonne, 1998). There are several possible explanations for the discrepant findings. One possibility is the instrument used to guide the clinician's diagnosis of autism, the ADOS-G, is limited in its ability to discriminate autistic disorder from PDD-NOS (Lord, 1998). However, the mean scores were similar for functioning assessed by the ADOS-G (i.e., social, communication and repetitive behaviors domains) to the mean values from the sample used to develop the norms for the ADOS-G. Such similarity suggests we did not overdiagnose autistic disorder relative to the normative data. Another possible explanation is that our method of case identification was not good at identifying children with other spectrum disorders. Our method of case finding assumed that the autistic behaviors of children would be recognized and/or

described previously by someone--an educator, parent or clinician--even in the absence of a formal autism diagnosis or classification. Some children with PDD-NOS or Asperger's disorder may function well in the community and therefore may have been missed by our case-finding process.

We observed several well-established epidemiologic characteristics of children with autism in this investigation, although the strength of the associations were perhaps less remarkable than in most previous studies. These characteristics included the predominance of males and the high proportion of children with co-existing mental retardation. The male-to-female ratios found in other studies have ranged from about 2:1 to 4:1 with a few exceptions of very high ratios (see Table 6). Thus, the 2.2 male-to-female prevalence ratio for autistic disorder observed in Brick Township is at the lower end of the range found in other studies. The higher male-to-female ratio for PDD-NOS/Asperger's disorder than for autistic disorder seems unusual, however, less is known about epidemiologic characteristics of this clinical entity and as noted, we may have missed children with other spectrum disorders. Similarly, we found about two thirds of the children with autistic disorder and slightly less than half the children with PDD-NOS had co-existing mental retardation. The prevalence of co-existing mental retardation in prior studies ranged from 44% to 100%, with the majority of studies in the 60%- 80% range. The proportion of case-children in Brick Township with mental retardation was at the lower end of this range. Possible explanations included the intelligence test used, the Differential Abilities Scale, which is a preferred test for children with autism because it minimizes the level of verbal abilities needed to complete the tasks in comparison to other standardized IQ tests (Tager-Flusberg and Joseph, 1999). Also, the growing availability of early intervention services may impact the level of functioning for the group of children from this community. Finally, if children without IQ information were lower functioning than children for whom IQ information was available, the proportion with mental retardation would have been higher.

Epilepsy has been found in other investigations as the second most common co-existing medical condition among children with autism, occurring in up to 25% of case children; other medical conditions occur much less frequently (Fombonne et al., 1997; Gillberg et al., 1994; Sponheim & Skejeldal, 1998). Associated medical conditions of any type were reported in just five (8%) the case children in Brick Township. Only two of these children (3%) were reported to have epilepsy.

The strong genetic component of autism has been well described in family and twin studies (Szatmari, 1998; Spiker, 1999). In this investigation, 7% of the 57 families had more than one child with an ASD; the rate of ASD in siblings was 5%. Genetic family studies had found rates of ASD of 5-6% in siblings (Szatmari et al., 1998), suggesting that Brick Township is within the range of what has been observed previously.

While we obtained permission to review records from most potential case sources, there were three physicians identified as possible sources who elected not to participate. Although the names of only one of these physicians was noted in the chart review at other sources, it is unknown whether additional case children would have been identified from their practices. This might be especially true for higher functioning children who were not known to other sources.

One possible explanation for a high rate of autism in Brick Township is that families with children with already diagnosed ASD were more likely to have moved into Brick Township than other families. Although we did not have specific information about the changes in the Brick Township population over time, we do know that about one third of the families with children with ASD who were included in the study moved into Brick Township sometime after their child's birth. This rate of in-migration is comparable to the rate of growth experienced by the Brick Township schools where the elementary school population increased 25% in the 9-year interval from 1990 to 1998.

Conclusions

Our investigation found high rates of autistic disorder and ASD in Brick Township relative to rates from previously published studies. The rates for the majority of recent studies are several fold lower than the

rate in Brick Township. However, a few, very recent studies yield rates close to those in Brick Township. These studies, like the Brick Township investigation, tended to use relatively intense case-finding methods. In Brick Township, the relatively small size of the target population; the heightened awareness of parents, teachers, and clinicians; and the full cooperation of most of the service providers allowed for thorough case-finding. The use of the ADOS-G may have contributed to the high rate of autistic disorder because children with more subtle signs of an ASD may have been included as cases. At the same time, comparability between epidemiologic characteristics of children with ASD in Brick Township and those in previous studies attest to the validity of our methods.

Although progress has been made in understanding this complex neurobehavioral disorder, a great deal of research still remains. The important population-based research that will provide full understanding of the magnitude of this important public health problem and identification of potential risk factors has only recently begun in the United States. To best interpret the rate of autism in Brick Township, we need comparable data on the prevalence of autism from a number of large and diverse populations in the United States. Such studies must use standardized case-finding methods and similar diagnostic tools to enable comparisons of rates across different geographic areas and across other population characteristics, and to identify potential causes for autism.

Subsequent steps may include conducting a large community-based case-control study of autism in Brick Township and in several other communities in New Jersey. This investigation could include a prevalence phase, to compare the prevalence rates of autism in Brick Township and surrounding communities with other areas in New Jersey. An analytic phase could examine the roles of various genetic, infectious, immunologic, and environmental factors in the etiology of autism.

References

Arvidsson, T., Danielsson, D., Forsberg, P., Gillberg, C., & Johansson, M. (1997). Autism in 3-6-year-old children in a suburb in Goteborg, Sweden. Autism, 1, 163-173.

Baird, G., Charman, T., Baron-Cohen, S., Cox, A., Swettenham, J., Wheelwright, S., Drew, A., & Kemal, L. (in press). A screening instrument at 18 months of age: A six-year follow-up study. Journal of the American Academy of Child and Adolescent Psychiatry.

Baron-Cohen, S., Cox, A., Baird, G., Swettenham, J., Nightingale, N., Morgan, K., Drew, A., & Charman, T. (1996). Psychological markers in the detection of autism in infancy in a large population. British Journal of Psychiatry, 168, 158-163.

Berry, K. E. (1997). Developmental Test of Visual-Motor Integration (fourth edition). Modern Curriculum Press.

Bohman, M., Bohman, I.L., Bjorck, P.O., & Sjoholm, E. (1983). Childhood psychosis in a northern Swedish county: Some preliminary findings from an epidemiological survey. In M.H. Schmidt & H. Remschmidt (Eds.), Epidemiological Approaches in Child Psychiatry. pp 164-173 Verlag: Stuttgart.

Brask, B.H. (1970). A prevalence investigation of childhood psychoses. In Nordic Symposium on the Care of Psychotic Children, pp 145-153. Trykningssentral: Oslo.

Bryson, S.E., Clark, B.S., & Smith, I.M. (1988). First report of a Canadian epidemiological study of autistic syndromes. Journal of Child Psychology and Psychiatry, 29, 433-445.

Bryson, S.E, & Smith, I.M.. (1998). Epidemiology of autism: prevalence, associated characteristics, and implications for research and service delivery. Mental Retardation and Developmental Disabilities Research Review, 4, 97-103.

Burd, L., Fisher, W., & Kerbeshian, J. (1987). A prevalence study of pervasive developmental disorders in North Dakota. Academy of Child and Adolescent Psychiatry, 26, 700-703.

California Department of Developmental Services. (March, 1999) Changes in the population of persons with autism and pervasive developmental disorders in California's Developmental Services System: 1987 through 1998. A Report to the Legislature, Department of Developmental Services, Sacramento.

Cialdella, P., & Mamelle, N. (1989). An epidemiological study of infantile autism in a French department (Rhone): A research note. Journal of Child Psychology and Psychiatry, 30, 165-175.

Deb, S. & Prasad, K.B. (1994). The prevalence of autistic disorder among children with learning disabilities. British Journal of Psychiatry, 165, 395-399.

Elliott, C. D. (1990). Differential Ability Scales. The Psychological Corporation: New York.

Filipek, P.A., Accardo, P.J., Baranek G.T., Cook, E.H., Dawson, G., Gordon, B., Gravel., J., Johnson, C.P., Kallen, R.J., Levy, S.E., Minshew, N.J., Prizant, B.M., Rapin, I., Rogers, S.J., Stone, W.L., Teplin, S., Tuchman, R.F., & Volkmar, F.R. (1999). The screening and diagnosis of autism spectrum disorders. Journal of Autism and Developmental Disorders, 29, 437-481.

Fombonne, E., & du Mazaubrun, C. (1992). Prevalence of infantile autism in four French regions. Social Psychiatry and Psychiatric Epidemiology, 27, 203-210.

Fombone E., du Mazaubrun, C. du, Cans, C., & Grandjean, H. (1997). Autism and associated medical disorders in a French epidemiologic survey. Journal of the American Academy of Child Adolescent Psychiatry, 36, 1561-1569.

Fombonne, E. (1998). Inflammatory bowel disease and autism. Lancet, 351, 955.

Fombonne E. (1999). The epidemiology of autism: A review. Psychological Medicine, 29, 769-786.

Gillberg, C. (1984). Infantile autism and other childhood psychoses in a Swedish urban region. Epidemiologic aspects. Journal of Child Psychology and Psychiatry, 25, 35-43.

Gillberg, C., Gillberg, I.C., & Ahlsen, G. (1994). Autistic behaviour and attention deficits in tuberous sclerosis: A population-based study. Developmental Medicine and Child Neurology, 36, 50-56.

Gillberg, C., Steffenburg, S., & Schaumann, H. (1991). Is autism more common now than ten years ago? British Journal of Psychiatry, 158, 403-409.

Gillberg, C., & Wing, L., (1999). Autism: Not an extremely rare disorder. Acta Psychiatrica Scandinavica, 99, 399-406.

Honda, H., Shimizu, Y., Misumi, K., Niimi, M., & Ohashi, Y. (1996). Cumulative incidence and prevalence of childhood autism in children in Japan. British Journal of Psychiatry, 169, 228-235.

Hoshino, Y., Yashima, Y., Ishige, K., Tachibanam, R., Watanabe, M., Kancki, M., Kumashiro, H., Ueno, B., Takahashi, E., & Furukawa, H. (1982). The epidemiological study of autism in FukushimaKen. Folia Psychiatrica et Neurologica Japonica, 36, 115-124.

Ishii, T. & Takahashi, I. (1983). The epidemiology of autistic children in Toyota, Japan: Prevalence. Japanese Journal of Child and Adolescent Psychiatry, 24, 311-321.

Kadesjo, B., Gollberg, C., & Hagberg, B. (1999). Autism and Asperger Syndrome in seven-year-old children: A total population study. Journal of Autism and Developmental Disorders, 29, 327-331.

Kanner, L., & Eisenberg, L. (1956). Early infantile autism 1943-1955. American Journal of Orthopsychiatry, 26, 55-65.

International Statistical Classification of Diseases and Related Health Problems (ICD), Tenth Revision. (1992). Geneva: World Health Organization.

Lord, C. (1998). The Autism Diagnostic Observation Schedule-Generic (ADOS-G). Paper presented at the NIH State of the Science in Autism: Screening and Diagnosis Working Conference, Bethesda, MD.

Lord, C., & Risi, A. (1998). Frameworks and methods in diagnosing autism spectrum disorders. Mental Retardation and Developmental Disabilities Research Reviews, 4, 90-96.

Lord, C., Rutter, M., Goode, A., Heemsbergen, J., Jordan, H., Mawhood, L., & Schopler, E. (1989). Autism Disagnositc Observation Schedule: A standardized observation of communicative and social behavior. Journal of Autism and Developmental Disorders, 19, 185-212.

Matuishi, T., Shiotsuki, Y., Yoshimura, K., Shoji, H., Imuta, F., Yamashita, F. (1987). High prevalence of infantile autism in Kurume City, Japan. Journal of Child Neurology, 2, 268-271.

McCarthy, P., Fitzgerald, M. & Smith, M.A. (1984). Prevalence of childhood autism in Ireland. Irish Medical Journal, 77, 129-130.

Ritvo, E.R., Freeman, B.J., Pingree, C., Mason-Brothers, A., Jorde, L., Jenson, W.R., McMahon, Petersen, P.B., Mo, A. & Ritvo, A. (1989). The UCLA-University of Utah epidemiologic survey of autism: prevalence. American Journal of Psychiatry, 146, 194-199.

Sparrow, S. S., Balla, D. A., & Cicchetti, D. V. (1984). Vineland Adaptive Behavior Scales (survey edition). American Guidance Service: Circle Pines, MN.

Spiker, D. (1999). The role of genetics in autism. Infants and Young Children, 12, 55-63.

Sponheim, E., & Skjeldal, O. (1998). Autism and related disorders: Epidemiological findings in a Norwegian study using ICD-10 diagnostic criteria. Journal of Autism and Developmental Disorders, 28, 217-227.

Steinhausen, H., Gobel, D., Breinlinger, M., & Wohlleben, B. (1986). A community survey of infantile autism. Journal of the American Academy of Child Psychiatry, 25, 186-189.

Sugiyama, T., & Tokuichiro, A. (1989). The prevalence of autism in Nagoya, Japan: A total population study. Journal of Autism and Developmental Disorders, 19, 87-96.

Szatmari, P., Jones, M.B., Zwaigenbaum, L., & MacLean, J.E. (1998). Genetics of autism: Overview and new directions. Journal of Autism and Developmental Disorders, 28, 351-368.

Tager-Flusberg, H., Joseph, R.M. (1999). A comparison of language abilities in high- and low-functioning children with autism. Paper presented at the Biennial Meeting of the Society for Research in Child Development. Albuquerque, New Mexico.

Tanoue, Y., Oda, S., Asano, F., & Kawashima, K. (1988). Epidemiology of infantile autism in southern Ibaraki, Japan: differences in prevalence in birth cohorts. Journal of Autism and Developmental Disorders, 18, 155-166.

Treffert, D.A. (1970). Epidemiology of infantile autism. Archives of General Psychiatry, 22, 431-438.

Webb, E.V.J., Lobo, S., Hervas, A., Scourfield, J., & Fraser, W.I. (1997). The changing prevalence of autistic disorder in a Welsh health district. Developmental Medicine and Child Neurology, 39, 150-152.

Wing, L. (1993). The definition and prevalence of autism: A review. European Child Adolescent Psychiatry, 2, 61-74.

Wing, L., & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. Journal of Autism Developmental Disorders, 9, 11-2.

Wing, L. (1981). Sex ratios in early childhood autism and related conditions. Psychiatry Research, 5, 129-137.

Prevalence of Autism in Brick Township, New Jersey, 1998: Community Report

Centers for Disease Control and Prevention
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Table 1. Children Identified as Possible Case-Children by Source of Diagnostic Information and Final Diagnosis.

Source of Diagnostic Information

Final Diagnosis	Clinical Exam	Records	Total
Autism Spectrum Disorder (ASD)	43	17	60
Autistic disorder	30	6	36
PDD-NOS / Asperger disorder	13	11	24
Not ASD	10	5	15
Total	53	22	75

Table 2. Prevalence of Autism Spectrum Disorder (ASD) in Brick Township, NJ, by Age in 1998.

Age in 1998

Diagnosis	3-5 years (N= 3,479)		6-10 years (N=5,417)		3-10 years (N=8,896)	
	No.	Rate/1,000 (95% CI)	No.	Rate/1,000 (95% CI)	No.	Rate/1,000 (95%CI)
Autistic disorder	19	5.5 (3.3 - 8.5)	17	3.1 (1.8 - 5.0)	36	4.0 (2.8 -5.6)
PDD-NOS/Asperger's disorder	8	2.3 (1.0-4.5)	16	3.0 (1.7-4.8)	24	2.7 (1.7-4.0)
Total ASD	27	7.8 (5.1-11.3)	33	6.1 (4.2–8.5)	60	6.7 (5.1 - 8.7)

PDD-NOS = pervasive developmental disorder–not otherwise specified

Table 3. Prevalence of Autism Spectrum Disorder (ASD) in Brick Township, NJ, by Sex

Diagnosis	Male (N= 4,532)		Female (N=4,364)			
	No.	Rate/1,000 (95% CI)	No.	Rate/1,000 (95% CI)		Male/Female Prevalence Ratio
Autistic disorder	25	5.5 (3.6 -8.1)	11	2.5 (1.3 - 4.5)		2.2 (1.1 - 4.4)
PDD-NOS/ Asperger's disorder	19	4.2 (2.5-6.5)	5	1.1 (0.4-2.7)		3.7 (1.4-9.8)
Total ASD	44	9.7 (7.1- 13.0)	16	3.7 (2.1 - 5.9)		2.7 (1.5-4.7)

PDD-NOS - pervasive developmental disorder– not otherwise specified

Table 4. Distribution of Intellectual Quotient (IQ) Score* by Autism Spectrum Disorder Diagnosis (ASD).

IQ Score

	<50	**50 - 70**	**71 - 85**	**>85**	**Not testable****
Diagnosis	**No. (%)**	**No. (%)**	**No. (%)**	**No. (%)**	**No. (%)**
Autistic disorder (N=30)	6 (20)	9 (30)	6 (20)	5 (17)	4 (13)
PDD-NOS/ Asperger's disorder (N=15)	0 (0)	6 (40)	4 (27)	5 (33)	0 (0)
All ASD (N=45)	6 (13)	15 (33)	10 (22)	10 (22)	4 (9)

*** IQ information was not available for 15 children.**
**** Four children could not complete testing with the DAS because of limited language ability and/or cooperation. These children were considered to have moderate to severe mental retardation with Vineland composite and communication standard score of less than 50.**
PDD-NOS = Pervasive developmental disorder–not otherwise specified

Table 5. Number of Children with Autism Spectrum Disorder (ASD) who have Siblings with a Developmental Disability, by Diagnosis .

Diagnosis	Number of case children with diagnosed siblings
ASD	7**
Non-ASD developmental disability*	6
Attention deficit hyperactivity disorder	3
Speech/language/auditory disorders	2
Down syndrome	1
Cerebral palsy	1

**** Three sibling pairs (including 6 case-children) from three families were included in the prevalence study.**

*** Numbers total 7 because one child had two siblings with different DD's.**

Table 6. Summary of Epidemiologic Studies Examining the Prevalence of Autism, by Characteristics of the Studies

Author	Diagnostic Criteria	Rate/1,000 (95% CI)*	No. Children with Autistic Disorder	No. Children in Population	Male/Female Ratio	IQ #70 %
Lotter, 1966	Kanner	0.45 (0.31-0.62)	35	78,000	2.6	84
Brask, 1972	Kanner	0.43 (0.26-0.66)	20	46,500	1.5	-
Wing & Gould, 1979	Kanner	0.49 (0.29-0.78)	17	34,700	16.0	70
Hoshino et al., 1982	Kanner	0.23 (0.19-0.27)	142	609,848	9.9	-
Ishii & Takahashii, 1983	DSM III	1.60 (1.21-2.08)	56	35,000	6.0	-
Bohman et al., 1983	Rutter	0.56 (0.40-0.77)	39	69,000	1.6	80
Gillberg, 1984	DSM-III	0.40 (0.30-0.52)	51	128,600	1.8	78
McCarthy et al., 1984	DSM III	0.43 (0.29-0.62)	28	65,000	1.3	-
Steinhausen et al., 1986	Rutter	0.19 (0.14-0.24)	52	279,616	2.3	-
Matsuishi et al., 1987	DSM-III	1.55 (1.16-2.04)	51	32,834	4.0	nr
Burd et al., 1987	DSM-III	0.33 (0.25-0.42)	59	180,986	2.7	nr
Bryson et al., 1988	DSM-III-R	1.01 (0.62-1.54)	21	20,800	2.5	76
Tanoue et al., 1988	DSM-III	1.38 (1.16-1.64)	132	95,394	4.1	nr
Ritvo et al., 1989	DSM-III	0.25 (0.21-0.28)	241	769,620	3.7	66
Cialdella & Mammelle, 1989	Rutter	0.45 (0.34-0.56)	61	135,180	2.0	nr
Sugiyama & Abe, 1989	DSM-III	1.30 (0.74-1.95)	16	12,263	nr	nr
Gillberg et al., 1991	DSM-III-R	0.95 (0.74-1.19)	74	78,100	2.9	82
Fombonne & du Mazaubrun, 1992	DSM-III	0.49 (0.41-0.57)	154	274,816	2.1	87
Webb et al., 1997	DSM-III-R	0.72 (0.54-0.95)	53	73,301	6.6	-
Baron-Cohen et al., 1996	ICD-10	0.63 (0.30-1.15)	10	16,000	nr	-

Honda et al., 1996	ICD-10	2.11 (1.26-3.35)	18	8,537	2.6	50
Fombonne et al., 1997	ICD-10	0.54 (0.46-0.62)	174	325,347	1.8	88
Arvidsson et al., 1997	ICD-10	3.10 (1.16-6.84)	6	1,941	5.0	100
Sponheim & Skejeldal, 1998	ICD-10	0.38 (0.25-0.56)	25	65,688	1.9	64
Kadesjo, Gillberg & Hagberg, 1999	ICD-10	6.00 (1.90-14.10)	5	826	**	60
Baird, et al., in press	ICD-10	3.08 (2.29- 4.06)	50	16,235	15.7	40

*** Confidence intervals computed by authors.**
**** All 5 children were boys**