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**Brief Report: Prevalence of Autism Spectrum Conditions in
Children Aged 5 – 11 Years in Cambridgeshire, UK.**

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Abstract

Background: There have been few prevalence studies of autism in the UK since the early 1980's, and few prevalence studies either nationally or internationally which have included broader autism spectrum conditions (ASC) (Fombonne, 1999). Those that have present with varying figures (e.g., Baird et al., 2000; Kielinen et al., 2000). The present study aimed to establish prevalence of the broader spectrum, including Asperger Syndrome, in 5-11 year olds in Cambridgeshire, UK in comparison to other recent reported rates.

Method: Cases of diagnosed ASC in children in Cambridgeshire schools aged between 5 and 11 years in July - December 1999 were sought using public records, screening instruments, and educational psychology and Special Education Coordinating Officer (SENCO) records.

Results: We report a prevalence of ASC in the age-group 5-11 yrs of almost 0.6% (57 in 10,000). This is 11 times higher than the rate of classic autism but in line with other recent national and international rates for the broader spectrum. Half the responding mainstream primary schools had at least 1 child with an ASC. In the responding mainstream schools the prevalence was 0.33%. In the responding special needs population it was 12.5%. The overall sex ratio of the children with ASC replicated earlier findings of 4:1 (m:f), but in those children being educated in mainstream schools the sex ratio was 8:1 (m:f).

Conclusion: These estimates have major implications for service planning and epidemiology, and warrant further study both nationally and internationally.

Keywords: Autism, autism spectrum, epidemiology, prevalence.

The prevalence rate of classic autism is traditionally reported to be 4-5 per 10,000 children (0.04%) (Fombonne, 1999), but recent studies have suggested that this rate may be changing. For example, a study of prevalence of childhood autism in Iceland suggested a rate of 3.8 per 10,000 in a cohort of subject born between 1974 and 1983, but a rate of 8.6 per 10,000 in a cohort of subject born between 1984 and 1993 (Magnusson & Saemundsen, 2001), although the authors argue that this may well be a result of changing diagnostic criteria and awareness. Genetic studies have recently indicated that traditional diagnostic boundaries are too narrowly defined and that autism is just one part of a spectrum of disorder that encompasses other variants such as atypical autism, pervasive developmental disorder not otherwise specified and Asperger syndrome (Bolton, MacDonald, Pickles et al., 1994). The prevalence of the broader range of autistic spectrum conditions (ASC) is largely unknown. Wing and Gould (1979) suggested a rate of around 20 in 10,000 for the broader autism spectrum in children with associated learning difficulties, whilst a more recent study of ASC in 18 month olds suggested a lower prevalence rate of 6 in 10,000 (0.06%) (Baron-Cohen, Cox, Baird, Swettenham, et al., 1996). However this study was likely not to have identified children with Asperger syndrome as this form of disorder usually only presents clearly at a later age. The key prevalence study of Asperger Syndrome, in 8-16 yr olds, suggests a rate of 30 in 10,000 (0.3%) (Ehlers & Gillberg, 1993). A recent paper from the Centers for Disease Control for Brick Township, New Jersey reported a prevalence rate of autistic disorder in 3 - 10 year olds of 40 in 10,000 and up to 67 in 10,000 if children with PDD-NOS and AS were included in the figures (US CDC, 2000). Other recent findings for the prevalence of the broader autism spectrum range from 20.7 in 10,000 in the 5 - 7 year old population in

Northern Finland (Kielinen, Linna & Moilanen, 2000) to 57.9 per 10,000 in a cohort of children aged 7 in the South East of England (Baird, Charman, Baron-Cohen, et al., 2000). However, children with Asperger syndrome are typically not identified until around age 11 (Howlin & Moore, 1999), thus it is possible that many of these recent studies are under-estimations as they may not include more able children on the spectrum.

It is apparent from these recent papers that prevalence of the broader autism spectrum may be considerably higher than previously suspected, but with continued disagreement about the most likely 'true' figures. The aim of this study was to assess the prevalence of ASC in children aged 5 – 11 years (the primary school age population) during the period July 1999 – December 1999, to explore how the prevalence rates for the broad autism spectrum in this area of the UK would compare with other recent national and international findings. We were particularly interested in this age range because there should be minimum risk of false negatives by this age, and because we wished to include more able children with ASC's (such as Asperger Syndrome) who are not typically identified until around 11 years of age (Howlin & Moore, 1999).

Methods & Procedure

Cases of diagnosed ASC in children in Cambridgeshire schools aged between 5 and 11 years in July - December 1999 were sought, with the census day being December 31st

1999.¹ During this period Cambridgeshire had 43,472 children in this age range. This means the target population for our study will provide a smaller sample than is typically recommended for epidemiological research, which some authors suggest may affect reliability of prevalence estimates (e.g., Fombonne, 1999). However, the study has endeavoured to address the issue of reliability by counting only those children who have definite clinical diagnoses on the autism spectrum. Schools were identified via Local Education Authority (LEA) public records following appropriate ethical consent, and contacted directly. All Cambridgeshire schools with pupils aged 5 - 11 were contacted (n = 223, including special needs (n = 11) and independent schools (n = 12). Approximately 52% of schools were in Cambridge region, 27% in the Huntingdon region and 21% in the Peterborough region). Each school was sent a short form asking for numbers of children currently at the school with a diagnosis of ASC, including Asperger Syndrome, to be recorded.

As well as school information, we used the following additional criteria. Although cases were reported by the schools to be diagnosed clinically, the diagnostic information from schools was cross-checked with information from special needs services, from our own clinical records, and from educational psychologist services, using the child's date of birth and gender link records. Only those children who had been given a definitive clinical diagnosis of autism spectrum disorder (i.e., meeting DSM-IV or ICD-10 criteria) were counted in the study (with the autism spectrum being defined as: autism, atypical autism, Asperger syndrome, pervasive developmental disorder not-otherwise-specified).

¹ Although it took around 6 months to collate the data from all sources, the schools were contacted before the end of the summer term so that there would not be an overlap with new pupils starting after summer.

In addition, a random subset of parents of one quarter of the children identified were sent the Autism Screening Questionnaire (n = 56) (Kazak-Berument, Rutter, Lord, Pickles, & Bailey, 1999). The ASQ has demonstrated reliability in identifying children meeting ICD-10 criteria for ASC. Whilst the ASQ is a screening measure and not a diagnostic tool, it was used here as a means of checking for consistency in diagnoses between health regions (i.e., whether clinical diagnoses given also met ICD-10 research criteria for autism spectrum on the ASQ), and as a method of calibration to enable us to be as conservative as possible in our final figures. Parents were asked to indicate the precise diagnosis for their child, and who had made that diagnosis.²

Results

Replies were received from 162 schools (72.6%), totalling 34,262 children (79% of the total 5-11 year population in Cambridgeshire). Of the non-responder schools, 7 were in the Huntingdon region (11% of the non-responders), 20 were in the Peterborough region (33% of non-responders), and 34 were in the Cambridge region (56% of non-responders). These proportions are not substantially different to those seen in the overall distribution of schools, suggesting that the differences between responder and non-responder schools are unlikely to be significant. Additionally, none of the non-responder schools were special schools or independent schools. Of the responder children 33,598 (98% of the responder total) attended mainstream schools and 664 (2%) attended special needs schools. 218 children (0.64%) were identified by the schools as having a diagnosis of

² Ideally, we would have liked to assess any identified children using ICD-10 criteria, but resources did not allow this for a brief study. Thus an ICD-10 screen on a subset was used in this instance.

ASC³. 196 of these (a prevalence of 57 in 10,000) also met our additional criteria (95% confidence interval (CI) = 49.5 - 65.8 in 10,000). (Due to the proportions involved, we calculated confidence intervals throughout using the exact method with binomial probabilities, to be as conservative as possible.) The remaining 22 either did not yet have an official diagnosis although were statemented (n=9 (41%)), did not meet ICD-10 research criteria with the ASQ (n=6 (27%)), or were missing data (n=7 (32%)).

Of the 196 children with confirmed ASC, 111 (0.33% of the responder population) were attending mainstream schools, and 85 (0.25%) were in special needs schools. 47% of responding mainstream schools for 5 – 11 year olds in Cambridgeshire have at least 1 child with a diagnosis on the autism spectrum. This prevalence is around 11 times higher than the traditional estimate for autism and around 3 times higher than the estimate for the broad autism spectrum suggested by Wing & Gould (1979) and Kielinen et al., (2000), (although Wing & Gould's data did not include more able children with autism spectrum diagnoses). The present results are comparable with the recent findings by Baird et al., (2000) or the Brick Township report (2000). Even if one assumes that none of the non-responder schools (totalling 9210 5-11 year old children) had any cases of ASC, the prevalence in this population in Cambridgeshire would be 50 in 10,000 (0.5%), 10 times the traditional estimate (95% CI = 39 - 52 in 10,000). Similarly, if one considers that the proportion of children who did not meet ICD-10 criteria with the ASQ is

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We were not able with this brief study to establish numbers of children in each diagnostic sub-category on the autism spectrum. Many diagnoses were listed as 'autism spectrum disorder' as a generic term thus we could not easily re-classify these cases as autism, atypical autism, Asperger syndrome or PDD-NOS without conducting our own research assessments. This was not practical with our resources, but is something which should be explored in future research.

reflective of the whole sample of identified cases, one could assume that around 19 cases from the whole sample should be disregarded (27%), leaving a total of 177. This would still lead to a prevalence of 52 in 10,000.

It should be emphasised, therefore, that these figures are conservative, particularly as they do not include those children who are awaiting confirmation of diagnosis (the delay between identification of difficulties and receipt of diagnosis is typically at least 12 months and can be longer than 3 years, Howlin & Moore, 1997).

The present study also found geographical variation. The Huntingdon area had 84 cases of ASC (out of 9955 children, a prevalence of 84 in 10,000; 95% CI = 67.4 – 104.3 in 10,000). The Cambridge area had 93 cases of ASC (out of 17312 children, a prevalence of 54 in 10,000; 95% CI = 43.4 – 65.8 in 10,000). The Peterborough area had 19 cases (out of 6995 children, a prevalence of 27 in 10,000; 95% CI = 16.3 – 42.3 in 10,000).

Since all these children met our criteria for ASC, and were recorded according to residence not location of school attended, the reason for this variation cannot be due to inaccurate diagnoses. It is more likely due to differences in awareness of ASC amongst professionals, or variations in service and funding availability. It is possible that there may have been some migration by families into particular areas where services are seen to be more available, or where there are a greater number of accessible special schools. This is something that should be considered in future studies of regional prevalence variations.

Finally, the present study also found an overall male:female (m:f) sex ratio of around 4:1, in line with traditional estimates (e.g., Fombonne, 1999). However, this varied by schooling, so that the m:f ratio in the ASC population attending special schools (with moderate to severe learning disability) was approximately 3:1, whilst the m:f ratio in the ASC population attending mainstream schools was 8:1.

Conclusions

Results from this study of the broader autism spectrum in 5-11 year old children in Cambridgeshire, UK, demonstrate that the numbers of children with autism spectrum disorders in this age range may be significantly greater than previously recorded, and support recent other research demonstrating higher prevalence figures nationally and internationally. It is not possible from this data to establish whether there has been an increase in incidence of autism, thus leading to greater prevalence figures overall, or whether changes in prevalence are in fact due to widening of diagnostic boundaries and better professional awareness. However, our conservative figures support the recent findings of Baird et al. (2000) and the Brick Township report (2000), and suggest that further more detailed epidemiological research is much needed to fully address such questions regarding incidence and presentation of the broader autism spectrum.

Within the present study, results suggest that 1 in every 2 mainstream schools in Cambridgeshire for this population has at least 1 child with a clinical diagnosis on the autistic spectrum, and that within the special needs population 1 in 8 children is

diagnosed on the autism spectrum. If this figure is replicated elsewhere it has important resource implications for the education service.

The findings of varying male:female ratios between mainstream schools and special schools are interesting. Whilst we cannot establish from our data exactly what factors might be involved, these results are in line with earlier suggestions that the male:female ratio for autism amongst children and adults with IQ's within the normal range (i.e., 70 and above) may be around 9:1 (Wing, 1981), and one might tentatively assume that many of the children with diagnosed ASC being educated in mainstream schools fall into this category.

Similarly, the findings of variance in prevalence between regions in Cambridgeshire are interesting. Our data cannot allow any real conclusions to be drawn as to why this might be the case - whether it is due to professional awareness and education, funding requirements, environmental factors, family migration, or the result of differing demographics. Future research is urgently needed to look into the epidemiology of autism spectrum conditions in order to address such questions adequately.

Overall, whilst it is difficult to compare prevalence across different age-group studies or across different regions, and the brief nature of this research study precludes us from having detailed sociodemographic data, the substantially higher prevalence figure for ASC reported here has important implications for service provision and for our understanding of the epidemiology of the autism spectrum, and as such these results merit testing both nationally and internationally.

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