Brief report
Prevalence of autism spectrum conditions in children aged 5–11 years in Cambridgeshire, UK

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ABSTRACT   The study aimed to establish prevalence of the broader autistic spectrum, including Asperger syndrome, in 5- to 11-year-olds in Cambridgeshire, UK. Cases of diagnosed autism spectrum condition (ASC) in children who were in Cambridgeshire schools and aged between 5 and 11 years on 31 December 1999 were sought using public records, screening instruments, educational psychology and special educational needs coordinator (SENCO) records. We report a prevalence of ASC in the age group 5–11 years of almost 0.6 percent (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. In the responding mainstream schools the prevalence was 0.33 percent. In the responding special school population it was 12.5 percent. The overall sex ratio of the children with ASC replicated findings for classical autism of 4:1 (M:F), but in those children being educated in mainstream schools the sex ratio was 8:1 (M:F).

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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 subjects born between 1974 and 1983, but a rate of 8.6 per 10,000 in a cohort of subjects born between 1984 and 1993 (Magnusson and

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Saemundsen, 2001). The authors argue, however, 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 (PDD-NOS) and Asperger syndrome (Bolton et al., 1994). The prevalence of the broader range of autistic spectrum conditions (ASCs) 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 ASCs in 18-month-olds suggested a lower prevalence rate of 6 in 10,000 (0.06%) (Baron-Cohen 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- to 16-year-olds, suggests a rate of 30 in 10,000 (0.3%) (Ehlers and Gillberg, 1993). A recent report from the Centers for Disease Control for Brick Township, New Jersey, reported a prevalence rate of autistic disorder in 3- to 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 (CDC, 2000). Other recent findings for the prevalence of the broader autism spectrum range from 20.7 in 10,000 in the 5- to 7-year-old population in northern Finland (Kielinen et al., 2000) to 57.9 per 10,000 in a cohort of children aged 7 in the south-east of England (Baird et al., 2000). However, children with Asperger syndrome are typically not identified until around age 11 (Howlin and Moore, 1999). Thus it is possible that many of these recent studies are underestimations as they may not include more able children on the spectrum.

It is apparent from these recent articles 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 ASCs in children aged 5–11 years (the primary school age population) as at 31 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 ASCs (such as Asperger syndrome) who are typically identified in later childhood (Howlin and Moore, 1999).

Methods and procedure

Cases of diagnosed ASC in children aged between 5 and 11 years in Cambridgeshire schools on the 31 December 1999 were sought. At this time

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Cambridgeshire had 43,472 children in this age range. This means the target population for our study provides a smaller sample than is recommended for epidemiological research, which in turn may affect the reliability of prevalence estimates (e.g. Fombonne, 1999). Whilst the present study may be affected by problems of reduced external reliability, the authors endeavoured to address the issue of internal 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 (n = 11) and independent schools (n = 12). Approximately 52 percent of schools were in the Cambridge region, 27 percent in the Huntingdon region and 21 percent 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 (identified for this study as being autism, atypical autism, pervasive developmental disorder not otherwise specified, and Asperger syndrome) to be recorded.

In addition to school information, we used the following 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 as defined above. We did not include children described as having 'autistic traits' or 'autistic features'. In addition, a random subset of parents of one-quarter of the children identified were sent the Autism Screening Questionnaire (n = 56) (Kazak-Berument et al., 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.[1]

Results

Replies were received from 162 schools (72.6%), totalling 34,262 children (79% of the total 5- to 11-year-old population in Cambridgeshire). Of the non-responder schools, seven were in the Huntingdon region (11% of the

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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 geographical differences between responder and non-responder schools are unlikely to be significant. We did not have information on social class, ethnic distributions etc. and so cannot address any possible differences according to those criteria. 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 schools. A total of 218 children (0.64%) were identified by the schools as having a diagnosis of ASC.[2] Of these, 196 (a prevalence of 57 in 10,000) also met our additional criteria (95% confidence interval (CI) = 49.5–65.8 in 10,000). (Owing 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 they had a statement of special needs that mentioned the possibility of autism ($n = 9$), or did not meet ICD-10 research criteria with the ASQ ($n = 6$), or were missing data ($n = 7$).

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 schools. Of responding mainstream schools for 5- to 11-year-olds in Cambridgeshire, 47 percent have at least one child with a diagnosis on the autism spectrum. This prevalence is around 11 times higher than the traditional estimate for autism and around three times higher than the estimate for autism and additional learning difficulties suggested by Wing and Gould (1979) and Kielinen et al. (2000) (Wing and 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) and the Brick Township report (CDC, 2000). Even if one assumes that none of the non-responder schools (containing a total of 9210 children age 5 to 11 years) 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 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 emphasized, 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

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receipt of diagnosis may be around 12 months and can be longer than 3 years (Howlin and Moore, 1997). It is likely that this varies with time and across regions. Waiting lists for diagnostic assessment in Cambridge, for example, are around 9 months, and many children will not get onto a waiting list immediately after initial identification of difficulties.

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 17,312 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. Given the lack of reliability in generalizing from such small numbers, the figures must be treated with caution. If they are accurate, they could result from differences in awareness of ASC amongst professionals, or variations in service and funding availability. It is also 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- to 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. However, the small numbers (in terms of epidemiological studies) means the results should be treated with caution. Even if they are accurate, it is not possible from these 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

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figures support the recent findings of Baird et al. (2000) and the Brick Township report (CDC, 2000), and suggest that further more detailed epidemiological research is needed to fully address such questions regarding incidence and the presentation of the broader autism spectrum.

Within the present study, results suggest that one in every two mainstream schools in Cambridgeshire for this population has at least one child with a clinical diagnosis on the autistic spectrum, and that within the special school population one in eight 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 IQs 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. Even ignoring the inherent unreliability in the small numbers involved, potentially 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 and limited 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.

Parliamentary Group on Autism in the Houses of Parliament, Westminster, London, 15 May 2000.

Notes

1 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.

2 We were not able with this brief study to establish numbers of children in each diagnostic subcategory on the autism spectrum. Many diagnoses were listed as 'autism spectrum disorder' as a generic term: thus we could not easily reclassify 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.

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