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The incidence and prevalence of pervasive developmental disorders: a Danish population-based study

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ABSTRACT

Background. Based on prevalence studies and the few incidence studies of pervasive developmental disorders (PDDs) the prevalence and incidence of these disorders have been claimed to be increasing.

Method. The annual and age-specific prevalence and incidence rates of childhood autism, atypical autism, Asperger's disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS) in Denmark during the period 1971–2000 in children younger than 10 years were estimated using data from the Danish Psychiatric Central Register.

Results. A total of 2·4 million children younger than 10 years were followed and 2061 cases with the PDDs studied were identified. Generally, the prevalence and incidence rates of the PDDs studied were stable until the early 1990s after which an increase in the occurrence of all disorders was seen, until 2000. The annual incidence rate per 10 000 children younger than 10 years was 2·0 for childhood autism, 0·7 for atypical autism, 1·4 for Asperger's disorder, and 3·0 for PDD-NOS in 2000. We calculated a 'corrected' prevalence of childhood autism at 11·8, atypical autism at 3·3, Asperger's disorder at 4·7, and PDD-NOS at 14·6 per 10 000 children younger than 10 years on 1 January 2001.

Conclusions. We found that the estimated prevalences of the PDDs studied were probably underestimated. Furthermore, the increasing prevalence and incidence rates during the 1990s may well be explained by changes in the registration procedures and more awareness of the disorders, although a true increase in the incidence cannot be ruled out.

INTRODUCTION

The group of pervasive developmental disorders (PDDs) are characterized by qualitative impairment in social interaction and communication, and stereotyped repetitive behaviour (WHO, 1993). Included in the group are, among others, childhood autism, atypical autism, Asperger's disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS). To fulfil the criteria for childhood autism, the symptoms must be apparent before 3 years of age whereas atypical autism is applied when symptoms develop after 3 years of age; otherwise, qualitatively, insufficiently severe impairments in all three areas of behaviour are visible. Asperger's disorder was introduced in the diagnostic criteria of ICD-10 (WHO, 1993) and DSM-IV (APA, 1994) and is characterized by impairments in social interaction and stereotyped repetitive behaviour but no delay in language development. PDD-NOS is used to categorize cases who fall short of diagnostic criteria for the above-mentioned disorders.

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Several prevalence studies of childhood autism have been published, with rates from 4 to 17 per 10 000 children (Sponheim & Skjeldal, 1998; Powell *et al.* 2000; Chakrabarti & Fombonne, 2001; Croen *et al.* 2002; Lingam *et al.* 2003) but in recent studies rates as high as 30–60 per 10 000 children have been found (Kadesjo *et al.* 1999; Baird *et al.* 2000; Bertrand *et al.* 2001). Until now, only a few incidence studies of childhood autism have been carried out (Taylor *et al.* 1999; Powell *et al.* 2000; Dales *et al.* 2001; Kaye *et al.* 2001) and they are difficult to compare owing to differences in ascertainment and statistical methods. In a recent review by Fombonne (2003*a*) increasing prevalence rates of autism with time were found and he suggested that the increase be in part attributed to changes in case definition and improved awareness of the disorders.

With respect to Asperger's disorder and other PDDs epidemiological research in these disorders has only started in recent years. The prevalence of Asperger's disorder varied across studies from 0·3 to 48 per 10 000 children owing to methodological differences (Fombonne & Tidmarsh, 2003) but a prevalence of 2 per 10 000 children has been suggested (Fombonne, 2001). In some studies cases with PDD-NOS are grouped together with Asperger's cases and an estimated prevalence for this group of around 26 per 10 000 children has been found (Bertrand *et al.* 2001; Fombonne *et al.* 2001) whereas for the whole PDD group prevalence rates of between 34 and 67 per 10 000 children were found (Fombonne, 2003*a*; Gurney *et al.* 2003; Yeargin-Allsopp *et al.* 2003). However, in a study screening mainstream schoolchildren a conservative estimate of the prevalence of 20/10 000 for high-functioning PDDs including childhood autism, Asperger's syndrome, and PDD-NOS was made (Webb *et al.* 2003).

Recent reports have suggested that the occurrence of childhood autism and other PDDs may be increasing but the evidence regarding this remains controversial (Fombonne, 2003*b*). Several factors may have contributed to this apparent increase (Wing & Potter, 2002). First of all, the diagnostic criteria of childhood autism have broadened. Furthermore, it has been claimed that the increasing occurrence of autism is attributed mainly to an enlargement of the concept of PDDs to the categories Asperger's disorder and PDD-NOS. Also, more awareness of the disorders both among parents and professionals has occurred in recent years and an increasing number of centres have been established for children with autism and autistic-like behaviour. Moreover, it is well known among parents and professionals that early intervention and treatment can improve life for the child and family and a trend may be seen towards diagnosing the child with the most severe diagnosis in order to obtain the optimal amount of services.

Long-term trends of the prevalence and incidence of childhood autism, atypical autism, Asperger's disorder, and PDD-NOS in a total national population can be assessed in Denmark because admission to psychiatric hospitals has systematically been reported to a nationwide computerized registration system since 1969. The objective of our study was to assess if there had been any systematic change in the occurrence of these PDDs in the period 1971–2000.

METHOD

The Danish Psychiatric Central Register

The Danish Psychiatric Central Register (Munk-Jørgensen & Mortensen, 1997) is a nationwide computerized register established on 1 April 1969 which on a person-identifiable basis contains information about all admissions to psychiatric hospitals in Denmark with date(s) of admission(s) along with information on gender and date of birth. There are no private psychiatric hospitals in Denmark, and all treatment is free of charge. The coverage in the Danish Psychiatric Central Register has increased during the study period because of the following changes in the registration procedures:

(1) One of the main child psychiatric hospitals in Copenhagen did not report the diagnoses of their patients to the Danish Psychiatric Central Register until 1992. Since then this hospital has contributed approximately 20% of all cases of autism registered in Denmark.

(2) In 1994 the diagnostic criteria changed from ICD-8 (WHO, 1967) to ICD-10 (WHO, 1993). In the period of ICD-10 the degree of coverage by the Danish Psychiatric Central Register is believed to be high for childhood autism, and in a small sample the validity of this diagnosis was found to be high (Madsen *et al.*

2002). The validity of the other diagnoses, especially the ICD-8 diagnoses, is, however, believed to be lower.

(3) From 1 January 1995 out-patient activities were included in the register. In Denmark only a small proportion of cases with PDDs are admitted as in-patients, where in-patient refers both to children who stay at the hospital overnight and to children who come to the hospital on a daily basis for evaluation and treatment.

Note that patients are registered for each admission or out-patient contact. Therefore, some patients may have more than one diagnosis. Furthermore, where for some reason the first episode is not registered patients may be registered later.

Ascertainment of children with the PDDs studied

Age- and gender-specific information on the number of people alive and living in Denmark on 1 January is available for each year from 1971 onwards (Statistics Denmark, 2001). In this study we followed 2·4 million children of whom 1·8 million were followed from birth. We obtained information on all children who, from birth up to but not including their tenth birthday, were diagnosed with the PDDs studied in the period from 1 January 1971 to 31 December 2000. In this study we used time of diagnosis because time of onset is difficult to define and the disorder may in most cases be present at birth. The date of onset was defined as the first day of the first admission to a psychiatric hospital or the first contact with out-patient care with a diagnosis of childhood autism (ICD-8: 299·00, psychosis proto-infantilis or ICD-10: F84·0), atypical autism (ICD-8: 299·01, psychosis infantilis posterior or ICD-10: F84·1), or from 1994 onwards Asperger's disorder (ICD-10: F84·5), or PDD-NOS (ICD-10: F84·8, F84·9).

Calculation of incidence and prevalence

Incidence and prevalence rates were calculated for each year from 1971 to 2000 using the age- and gender-specific number of people in Denmark as a denominator. We divided age into the following bands: 0–1, 2–4, 5–6 and 7–9 years. For each year and age band, we calculated the incidence as the number of people who, in that age band and calendar year, were diagnosed with childhood autism, atypical autism, Asperger's disorder, or PDD-NOS *for the first time* divided by the total number of people alive and living in Denmark in that age band and year. Furthermore, for each age band and year, we calculated the 'estimated' prevalence as the number of people who, in that age band and calendar year (or previously), had *ever* been diagnosed with childhood autism, atypical autism, Asperger's disorder or PDD-NOS divided by the total number of people alive and living in Denmark in that age band and calendar year.

This study was approved by the Danish Data Protection Agency.

RESULTS

A total of 2061 children younger than 10 years of age were identified as having childhood autism, atypical autism, Asperger's disorder, or PDD-NOS. From 1971 to 2000, 759 children (78% males) were diagnosed with childhood autism, and 285 (73% males) were diagnosed with atypical autism. From 1994 to 2000, a total of 419 children (94% males) were diagnosed with Asperger's disorder and 806 (82% males) with PDD-NOS. Among children with childhood autism, atypical autism, Asperger's disorder and PDD-NOS a total of 135 (18%), 63 (22%), 60 (14%), and 153 (19%) respectively, were ever diagnosed with one of the other PDDs studied.

Incidence

Fig. 1 shows the incidence rates according to calendar year and age band for each diagnostic category: childhood autism, atypical autism, Asperger's disorder, and PDD-NOS. For each category the incidence was stable until 1990. After 1990 the incidence increased for all diagnoses in all age groups, except in children younger than 2 years of age where the incidences were nearly stable. In general, the highest rates were found for childhood autism and PDD-NOS. For childhood autism the largest incidence rates were found for the age band 2–4 years and in the group of cases with Asperger's disorder the largest rates were seen among children 5–9 years of age. We estimated the annual

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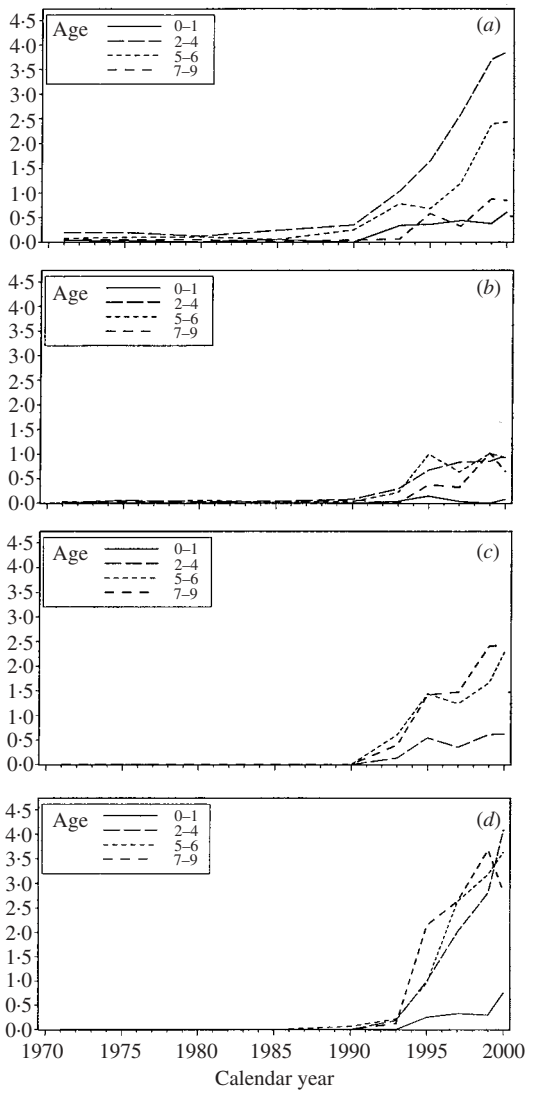

FIG. 1. Incidence of childhood autism (*a*), atypical autism (*b*), Asperger's disorder (*c*) and PDD-NOS (*d*) by age and calendar year. The incidence measures the number of new cases observed per 10 000 children per year. Each calendar year estimate of incidence was based on an average background population of 127 000, 194 000, 132 000 and 202 000 children aged 0–1, 2–4, 5–6 and 7–9 years respectively.

incidence of childhood autism at 2·0 [95% confidence interval (CI) 1·7–2·4], atypical autism at 0·7 (95% CI 0·5–0·9), Asperger's disorder at 1·4 (95% CI 1·1–1·7), and PDD-NOS at 3·0 (95% CI 2·6–3·4) per 10 000 children younger than 10 years in 2000. These estimates were based on the background population of all children younger than 10 years on 1 January 2001 (682 397 children).

Prevalence

Fig. 2 shows the 'estimated' prevalence of the diagnostic categories childhood autism, atypical autism, Asperger's disorder and PDD-NOS according to calendar year and age band. Until 1993 the 'estimated' prevalence rates were constant in all age groups and for all categories and since then the rates have increased in all age groups except for children younger than 2 years of age. We calculated an 'estimated' prevalence of childhood autism at 7·9 (95% CI 7·2–8·6), atypical autism at 2·8 (95% CI 2·5–3·3), Asperger's disorder at 3·7 (95% CI 3·2–4·1), and PDD-NOS at 8·7 (95% CI 8·1–9·5) per 10 000 children younger than 10 years on 1 January 2001. These estimates were based on the background population of all children younger than 10 years on 1 January 2001 (682 397 children).

We also analysed our data, excluding data from the child psychiatric hospital in Copenhagen, and a similar increasing trend in the incidence rates for childhood autism, atypical autism, Asperger's disorder, and PDD-NOS were observed until 1998 followed by decreasing rates (data not shown). Also, similar analyses were made excluding all outpatient activities and again a similar trend with increasing incidence rates until 1999 was observed although the increases were considerably lower (results not shown).

The estimated incidences and prevalences of the PDDs studied are most probably highly biased towards nil and only the age-specific incidence of the PDDs from the late 1990s may represent the true incidence of PDDs in the Danish population. If these arguments are valid we can calculate a more accurate measure of the true prevalence of PDDs; suppose that the age-specific incidence of PDDs has been constant the last 10 years at year 2000 level, the 'true' number of cases developing each year in each age group can be calculated by multiplying this age-specific incidence by the age-specific population size each calendar year. The corrected number of prevalent cases age 0–9 years on 1 January 2001 is then the summation of the cases in each age group and each calendar year, i.e. from 1990 to 2000. The corrected prevalence

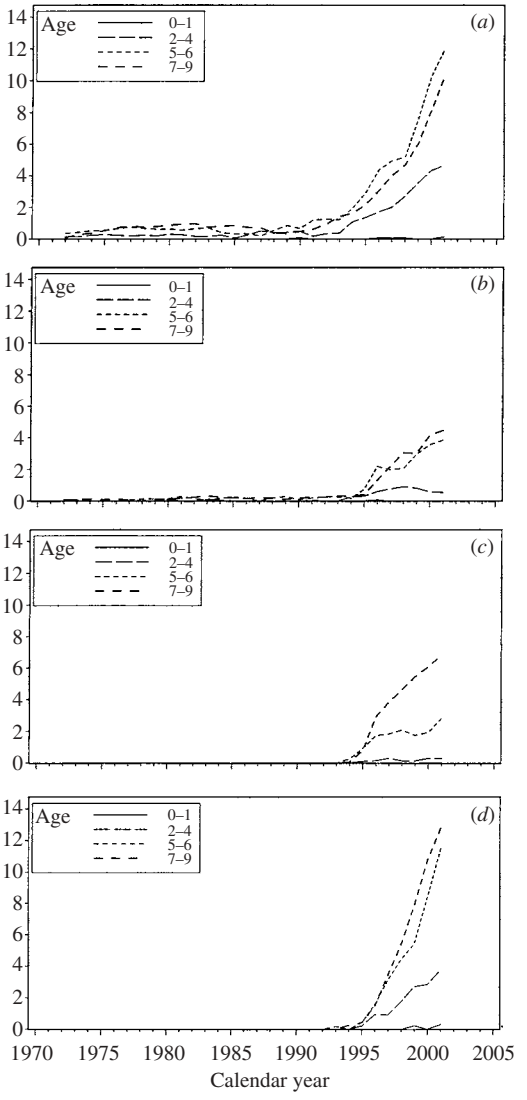

FIG. 2 'Estimated' prevalence of childhood autism (*a*), atypical autism (*b*), Asperger's disorder (*c*) and PDD-NOS (*d*) by age and calendar year. The prevalence measures the number of observed prevalent cases per 10 000 children. Each calendar year estimate of prevalence was based on an average background population of 127 000, 194 000, 132 000 and 202 000 children aged 0–1, 2–4, 5–6 and 7–9 years respectively.

is calculated by the corrected number of prevalent cases divided by the number of children age 0–9 years on 1 January 2001. We calculated a 'corrected' prevalence of childhood autism at 11·8, atypical autism at 3·3, Asperger's disorder at 4·7, and PDD-NOS at 14·6 per 10 000 children younger than 10 years on 1 January 2001.

DISCUSSION

Findings and limitations

To our knowledge this is the first population-based study of both the incidence and prevalence of PDDs covering a whole country. A large study population is investigated and Denmark is characterized by a very homogeneous and stable population with a low migration rate. However, the study is prone to bias due to changes over time in referral patterns, the hospital services available, awareness of PDDs, and the diagnostic concepts and practices. In general, increasing prevalence and incidence rates during the 1990s were found for all the PDDs studied and stabilization of all rates has not yet been seen. With respect to age groups the incidence rates were highest for the age group 2–4 years in children with childhood autism whereas for Asperger's disorder the largest incidence rates were found among the oldest children, reflecting different referral patterns for these two disorders.

Causes of increasing incidence of PDDs

The increasing prevalence and incidence rates in all diagnostic groups in the 1990s is most probably due to the changes in the registration procedures occurring in the Danish Psychiatric Central Register during the period 1992–1995: one of the main child psychiatric hospitals in Copenhagen did not report to the register until 1992; the diagnostic criteria changed from ICD-8 to ICD-10 on 1 January 1994; and out-patient activities were included in the register as of 1995. These changes will all lead to a more complete registration of children with PDDs. In addition, more awareness and broadening of the definition of PDDs will probably contribute to the increasing rates. However, except for cases with PDD-NOS the occurrence seems to increase 1–2 years before the official transition to ICD-10 in 1994, which could in part be explained by changes in conceptualization and classification of the disorders because draft guidelines of ICD-10 were widely circulated in Europe before 1994.

In what follows we argue that the increasing rates of PDDs presented in Figs 1 and 2 may be explained by the above-mentioned factors. When the incidence of a disorder is studied it

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is crucial that all cases with the disorder be registered at the time of onset (i.e. incident cases). Prevalent cases who are registered later may not be distinguished from incident cases, which may blur true time trends in incidence, or may even generate false time trends. Therefore, to ensure that only incident cases with PDDs are registered the children must be followed after the time of complete registration. Suppose that only a small proportion (say 5%) of the children with childhood autism and atypical autism were registered as incident cases in the Danish Psychiatric Central Register during the ICD-8 period and suppose that almost all children with the PDDs studied were registered as incident cases after the ICD-10 classification had been used for some years (e.g. from 1996). If the age of first admission with PDDs is from the second birthday, then the children followed after the time of complete registration must have been born in 1994 or later. According to the age bands used, i.e. 0–1, 2–4, 5–6 and 7–9 years, the condition of birth in 1994 or later is satisfied for calendar years 1996, 1999, 2001 and 2004 respectively. Based on these assumptions, Fig. 1 indicates the true incidence of the PDDs studied for age 0–1 years from 1996 to 2000, and Fig. 1 indicates the true incidence of PDDs for age 2–4 years from 1999 to 2000. The increase in incidence from 1990 to 2000 presented in Figs 1 and 2 satisfy these expectations of gradual increasing completeness of registration, and may therefore be subject to the changes mentioned earlier (missing reports of admissions from one of the child psychiatric hospitals in Copenhagen from 1992, changes in diagnostic criteria, and inclusion of out-patients), as well as more awareness of the PDDs both among parents and professionals.

Moreover, for childhood autism and most of the other PDDs the proportion of cases registered as new cases in each age band seems constant by year (Fig. 1) indicating that unregistered prevalent cases were not registered later as incident cases. If this were the case then the reported incidence for the age bands 5–6 and 7–9 years should have a higher estimated incidence than the age band 2–4 years.

In conclusion, based on these observations and our assumptions it may be reasonable to conclude that the age-specific incidence from the late 1990s may represent the true incidence in the Danish population, while all other reported rates are underestimated.

Comparison with other studies

When comparing the rates of autism and related disorders in different studies it is essential that the same concept of diagnoses is used. Because the 'estimated' prevalence rates of PDDs in this study are probably underestimated we calculated 'corrected' prevalences and we believe that these 'corrected' prevalences more accurately represent the true prevalence of the PDDs studied, although they are not based on observed data only. Generally, the 'corrected' prevalence rates calculated in our study are conservative estimates compared with the other studies made. The 'corrected' prevalence rate of childhood autism of 11·8 is comparable with some studies (Powell *et al*. 2000; Chakrabarti & Fombonne, 2001; Croen *et al*. 2002; Lingam *et al*. 2003) but other studies have found higher prevalence rates (Kadesjo *et al*. 1999; Baird *et al*. 2000; Bertrand *et al*. 2001). Our 'corrected' prevalence rate for Asperger's disorder of 4·7 is within the wide range of prevalence rates found in the few studies made and like others we found lower rates of Asperger's disorder relative to that of childhood autism (Fombonne & Tidmarsh, 2003). In order to compare rates of PDDs the 'corrected' prevalence rate of all the disorders in our study must be summarized and a total 'corrected' prevalence for the PDDs studied of 34·4 per 10 000 children on 1 January 2001 was found. This estimate is comparable with the 34 reported by Yeargin-Allsopp *et al*. (2003) whereas other studies found higher rates (Fombonne, 2003*a*).

However, several factors may contribute to the lower prevalence rates found in this study compared with other studies. First, this may reflect the study method, because in a register-based study based on routine hospital data, the number of cases included may be smaller than in a study screening a region for cases. In particular, some of the children fulfilling the diagnostic criteria of, for example, PDD-NOS or Asperger's syndrome may not be included because of very few behavioural problems and consequently no contact with psychiatric hospitals. Furthermore, cases with Asperger's syndrome diagnosed after the age of 10 years are missed because we decided only to follow the

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children for a diagnosis of Asperger's syndrome until the tenth birthday in order to facilitate internal comparison. Also, in 1993 a private diagnostic service called Center for Autisme, which does not report to the Danish Psychiatric Central Register, was established and some of the diagnostic evaluations of individuals with PDDs have been made there in recent years.

In this study increasing incidence and prevalence rates of PDDs during the 1990s were found. In the same period several changes occurred in the registration system which therefore most probably explains the increasing rates. There have been claims that the increasing rates of autism and other PDDs are caused by some unknown environmental exposure and this cannot be ruled out in this study. However, if the increase in incidence (and subsequently prevalence) is not caused by the above changes, then we need to argue the presence of some unknown exposure which affected children after 1990 resulting in a 20-fold increase in risk over a 10-year period. We believe that the presence of such an unknown risk factor coinciding with the changes in the registration system mentioned above is highly unlikely.

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DECLARATION OF INTEREST

None.

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