PostScript

LETTERS

Determining the true prevalence of autistic spectrum disorders

We read with interest the January edition of *Archives* containing three thought-provoking articles on the autistic spectrum. The article by Harrison *et al.*,¹ which described the two source "capture recapture" technique as a means of determining "true" prevalence, provided an enlightened alternative to using conventional, "passive" ascertainment of point prevalence. We conducted an 18-month retrospective audit of our social communication clinic for children in Enfield. The primary aim was to compare our clinic with the recommendations set by the National Autism Plan²; however, it also raised issues on:

1. the difficulties in obtaining accurate prevalence and incidence estimates; and
2. the effect of changes in child health surveillance policy.

Cases were identified from the Enfield social communication clinic referral dataset for the referral period January 2004–June 2005. A total of 124 children were referred during this period, of whom 66 fulfilled the criteria for autistic spectrum disorder (ASD; using either International Classification of Diseases—10th revision or the Diagnostic and Statistical Manual of Mental Disorders—IV revision). The birth rate in Enfield is about 4000 children/year. The age-related incidence of ASD was calculated looking at chronological years. In the age groups 2–3 and 3–4 years, for which 40 patients were diagnosed over an 18-month period, we found an age-specific incidence of 33.2/10 000 children/year. This is considerably higher than the incidence rate of 8.3/10 000 reported by Powell *et al.*,³ who looked at preschool children being diagnosed in the West Midlands between 1991 and 1996. Published prevalence estimates are, however, highly variable as shown by the recent systematic review by Williams *et al.*,⁴ ranging from 3.3 to 121/10 000 children, largely dependent on diagnostic criteria, age of assessment and case-load location.

Enfield's Pupil Level Annual School Census records from 2005 show that the Local Education Authority (LEA) was aware of 255 children known to have a diagnosis of ASD (point prevalence of 46/10 000). Capture and recapture methods applied to special educational needs data and our records over a longer period of time would be expected to give a truer picture of the incidence and prevalence of ASD.

We were surprised by Harrison *et al.*'s¹ data from Scotland, where only 5% of patients were <4 years of age. In all, 60% of the children diagnosed in our social communication clinic fell within the 2–4-year age group. We speculate that this is primarily due to our referral patterns (fig 1).

We found that 26% of our referrals came from health visitors after the 2-year checks. This suggests that routine surveillance is making a considerable contribution to the early detection of autistic spectrum disorders in Enfield. This has been documented by other

Figure 1 Source of referrals to Social Communication Clinic. ENT, ear, nose and throat; EP, educational psychologist; GP, general practitioner; HV, health visitor; OT, occupational therapist; SENCO, special educational needs coordinator; SLT, speech and language therapist; SN, school nurse.

investigators. Tebruegge *et al.*⁵ conducted a retrospective study of year 4 pupils attending 74 schools in Maidstone, and found that 68% of children diagnosed with ASD had been referred for further assessment as a consequence of routine 2–3 year checks. The uptake rate of the 2-year check offered by health visitors in Enfield is around 80% (Profit Impact of Marketing Strategies Data 2001); the 2-year check provides, and is a good opportunity for communication difficulties to be picked up in a culturally diverse area where questionnaire-based assessments are less effective. Unfortunately, the extent of this contribution to Enfield will only be clear when the current local practice is discontinued.

Clearly, barriers to sharing database information are found across agencies, but the ability to share such information would help ascertain not only the "true" prevalence of ASD but also local demographical needs, enabling comprehensive planning and provision of services.

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References

- 1 Harrison MJ, O'Hare AE, Campbell H, *et al.* Prevalence of autistic spectrum disorders in Lothian, Scotland: an estimate using the "capture-recapture" technique. *Arch Dis Child* 2006;91:16–19.
- 2 National Autism Plan for Children, March 2003. Published by the National Autistic Society for NIASA in collaboration with The Royal College of Psychiatrists, The Royal College of Paediatrics and Child Health (RCPCH) and the All Party Parliamentary Group on Autism (APPGA). www.nas.org.uk (accessed 23 Sep 2006).
- 3 Powell JE, Edwards A, Edwards M, *et al.* Changes in the incidence of childhood autism and other autistic spectrum disorders in preschool children from two areas of the West Midlands, UK. *Dev Med Child Neurol* 2000;42:624–8.
- 4 Williams JG, Higgins JPT, Brayne CEG. Systematic review of prevalence studies of autism spectrum disorders. *Arch Dis Child* 2006;91:8–15.

- 5 Tebruegge M, Nandini V, Ritchie J. Does routine child health surveillance contribute to the early detection of children with pervasive developmental disorders? An epidemiological study in Kent, UK. *BMC Pediatrics* 2004;4:4.

A survey of palivizumab for infants with cystic fibrosis in the UK

Palivizumab is a humanised monoclonal antibody to respiratory syncytial virus (RSV) that has been advocated as a potential prophylactic treatment in at-risk infants (ex-preterm).¹ Infection with RSV in cystic fibrosis may be a factor in the development of early lung disease and acquisition of bacterial pathogens. We aimed to determine the number of infants with cystic fibrosis in the UK who would be potential candidates for palivizumab prophylaxis and to quantify hospitalisation rates and mortality from RSV in this cohort. We conducted a national questionnaire study of 42 cystic fibrosis centres over the winter RSV season of 2005–6. Data were sought on patient population (number of infants born after October 2004), admissions with RSV infection and palivizumab use. Testing for RSV infection occurred where clinically indicated. Questions were asked on the likelihood of prescribing palivizumab, if funding were not an issue, and on the significance of RSV infection in the pathogenesis of early cystic fibrosis lung disease (scale: 1, not likely to 10, very likely).

In all, 34 centres responded (81%). A total of 143 infants with cystic fibrosis aged <1 year (mean 4.2 infants/centre) were identified. Of these, 70 infants were diagnosed by newborn screening (48.6%); 16 (11.2%) of the 143 infants were hospitalised owing to RSV infection; none required paediatric intensive care unit admission and none died; 14 (9.8%) infants received palivizumab between three cystic fibrosis centres, and one of these infants was subsequently hospitalised with RSV infection (other risk factors for this infant were not reported). Two of the three centres that used palivizumab had a local funding agreement negotiated into annual costings and offered RSV prophylaxis to all their patients <1 year of age. The likelihood of prescribing palivizumab if funding were not an issue was rated as a median of 6.5. The significance of the role of RSV in the pathogenesis of early cystic fibrosis lung disease was rated as a median of 5.0.

This survey highlights several issues regarding treating infants with cystic fibrosis using palivizumab. Subjectively, most respondents consider RSV infection important in cystic fibrosis lung pathogenesis and, if funding were not an issue, would prescribe palivizumab. However, there are no data from randomised controlled trials to support this,² and our data suggest that designing such a trial would require an unfeasibly large number of participants to show a clinically relevant reduction in hospitalisation. Given the importance doctors place on the long-term consequences of RSV infection in cystic fibrosis pathogenesis, reduction in hospitalisation may not be an appropriate outcome measure. Again, studies that evaluate longer-term outcomes that correlate with respiratory well-being are impractical. We are in a difficult situation; there is no national guidance on the use of palivizumab for infants with cystic fibrosis, and it is unlikely that