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## **Autism: higher and higher**

One research finding that has emerged over the past decade years is simple to summarise – autism is more common than we previously recognised. However, this does not make it simple or straightforward to answer questions that follow – Has autism become more common and if so, why?

I was part of the team from the UK who reported what until then had been the highest prevalence rate for the broader autism spectrum of 1.16% in mid-childhood in an article published in the medical journal *The Lancet* five years ago (the memorably accurate *Daily Mail* headline was ‘Autism at a Record High’)<sup>1</sup>. Only a few years later in 2009 colleagues from the UK reported a prevalence figure of 1.57%, again for the broader autism spectrum<sup>2</sup>. A few months ago a study was published reporting the prevalence of autism spectrum disorders in South Korea to be 2.64% in mid-childhood<sup>3</sup>. Understandably it attracted significant media attention. These three studies are interesting because they focus on sample roughly of the same age, use somewhat overlapping but not identical methodological approaches (to screening, sampling and diagnosis). As one epidemiologist I am fortunate to work with would say; the studies have ‘complementary weaknesses’.

Over this decade the debates and discussions have attracted widespread comment and debate amongst the clinical and academic psychiatry communities but also across the media and public more generally. Much of the public debate has been discussion of what has caused to use an unhelpfully over-blown phrase - the ‘epidemic of autism’. Various environmental causes have been suggested, often without an accompanying scientific evidence-base; most notably thimerosal-containing vaccines in the USA and in the UK the measles, mumps and rubella (MMR) vaccination. There may have been a *real* rise in autism prevalence and (unknown) environmental factors might have played a role in this rise but, put simply, we don’t know that for sure. Within the scientific literature, the possible contributory factors that might explain higher *measured prevalence* in more recent epidemiological studies have been well-rehearsed. In brief: over time the diagnostic criteria have broadened, the diagnosis of ASD has been applied to children previously excluded (those with severe intellectual disability, above average intelligence, genetic syndromes, those with hearing and visual impairments), and prevalence study designs have improved therefore capturing more cases.

These considerations are all fine and reasonable but they do not allow me confidently as a scientist to answer the ‘big’ questions I framed at the beginning of the article. One reason why the question ‘Has there been a *real* increase in autism prevalence?’ remains unanswered is that we cannot quantify whether these factors account for *all* of the apparent increase in measured prevalence over time. One reason why counting autism is so difficult is that it is a behaviourally defined disorder. Whatever ‘state of the art’ instruments and measures are used to assess individuals a subjective judgement needs to be made against the diagnostic criteria. When you set a high threshold for who has autism the count is lower, and when you set a low threshold the count is higher. There is also some evidence that ‘culture drift’ in our understanding of what constitutes autism has changed over the decades, in ways that are hard to quantify and study.

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One interesting similarity across the two UK studies and the South Korean study is that within each children were identified who met diagnostic criteria for an autism spectrum disorder (at least according to the research teams conducting the studies) who had not been identified by local, community clinical services. Sometimes this meant that they had been recognised to have another development disorder but autism but in other cases no developmental or education needs had been recognised. Within any community it is important to recognise children with developmental problems in order to provide the best treatment, support to families and advice to educators. Perhaps the most remarkable figure in the Kim et al. article, one not directly highlighted by the authors, is the disparity between the half percent of children by mid-childhood recognised as having *any* disability and the two-and-a-half percent identified as having an ASD in the research study. From an external perspective I suspect that many readers will think that the former figure is an underestimate of need. The outstanding question, is whether the latter figure is an accurate estimate of need in South Korea or indeed in other communities<sup>4</sup>.

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1. Baird G, Simonoff E, Pickles A, Chandler S, Loucas T, Meldrum D, Charman T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *The Lancet*, 368, 210-215.
2. Baron-Cohen S, Scott FJ, Allison C, Williams J, Bolton P, Matthews FE, Brayne C. (2009). Prevalence of autism spectrum conditions: UK school-based population study. *British Journal of Psychiatry*, 194, 500-509.
3. Kim YS, et al. (2011). Prevalence of autism spectrum disorder in a total population sample. *American Journal of Psychiatry*, 168, 904-912.
4. Charman, T. (2011). The highs and lows of counting autism (Invited Editorial). *American Journal of Psychiatry*, 168, 873-875.

### **Epidemiological methods**

- All 3 studies used a three-phase screening, sampling and assessment method
- The target sample population are screened using a parent or teacher questionnaire
- A proportion of those scoring above the cut-point (and some of the those scoring below) are invited for a direct assessment
- Following assessment the research team make a decision as to which children meet clinical criteria for an autism spectrum disorder
- The findings from those children assessed can be 'weighted back' onto the whole population screened to produce a prevalence estimate
- Since such designs identify cases who have not been diagnosed by local services they tend to report higher prevalence estimates