The Rise and Rise of the Autism Diagnosis

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Epidemiological studies have shown that the prevalence of autism spectrum disorders (ASD) has risen sharply in the western world [1,2]. ASD is now thought to occur in approximately one in 100 people [3] having risen from an estimated 1 in 10,000 people in the 1960s [4]. This trend is illustrated in Figure 1. These data were taken from various US and European prevalence studies, each utilizing differing methods of case ascertainment. Despite methodological differences, this figure serves to broadly illustrate the exponential rise in ASD prevalence. The most recent estimate is that 1 in 88 US children have an autism spectrum disorder at age 8– the highest prevalence ever recorded [5].

Epidemiologists have argued that the rise can be explained by changes in diagnostic categorization, the inclusion of Asperger’s Syndrome in 1994, combined with increased awareness of the category and diagnostic substitution by practitioners in order to access ASD-direct ed resources [6]. Also, the diagnosis of successively younger cohorts of children has boosted the numbers. Greater awareness of autism by clinicians and parents is a likely explanation. Some have argued strongly against the notion of an autism ‘epidemic’ which is how the media has repeatedly characterized this steep increase [7]. However, many lay stakeholders disagree, arguing that shifts in diagnostic categorization cannot tell the whole story. Our previous work shows an underlying public concern that environmental influences may be partially to blame. Novel prenatal and perinatal medical practices, changing diet, shifting family structures and childhood social activities have all been the subject of lay theories to explain rising prevalence of autism [8]. Despite lack of association with ASD, concerns over vaccines, those containing Thimerosal, a mercury-based preservative, in the USA, and MMR in the UK, are sites of social mobilisation.

The jury is still out on the question of whether rising prevalence reflects a real increase in incidence, or whether is entirely an artifact of changing diagnostic criteria and increased awareness. Put another way: have symptom levels remained constant with diagnosis increasing, so the labels are simply applied to more children? Or have increases in the numbers of children diagnosed been accompanied by increases in behaviors and impairments symptomatic of autism spectrum disorders? An article in Pediatrics concluded that ‘the question of whether this historical increase can be fully accounted for by changes in diagnosis and classification remains open to debate [9]. More research is needed – for although studies have highlighted increasing prevalence of autism, research on the symptom levels in successive cohorts is scanty, particularly when linked to data on contemporaneous diagnosis. I am part of a UK-based team hoping to correct this – we aim to examine whether the rise in numbers of children diagnosed with ASD has been accompanied by increases in the number, severity and frequency of underlying symptoms. Hopefully the work will help to clarify this ongoing debate.

References

Figure 1: The rising prevalence of autism spectrum disorders over 50 years [10].