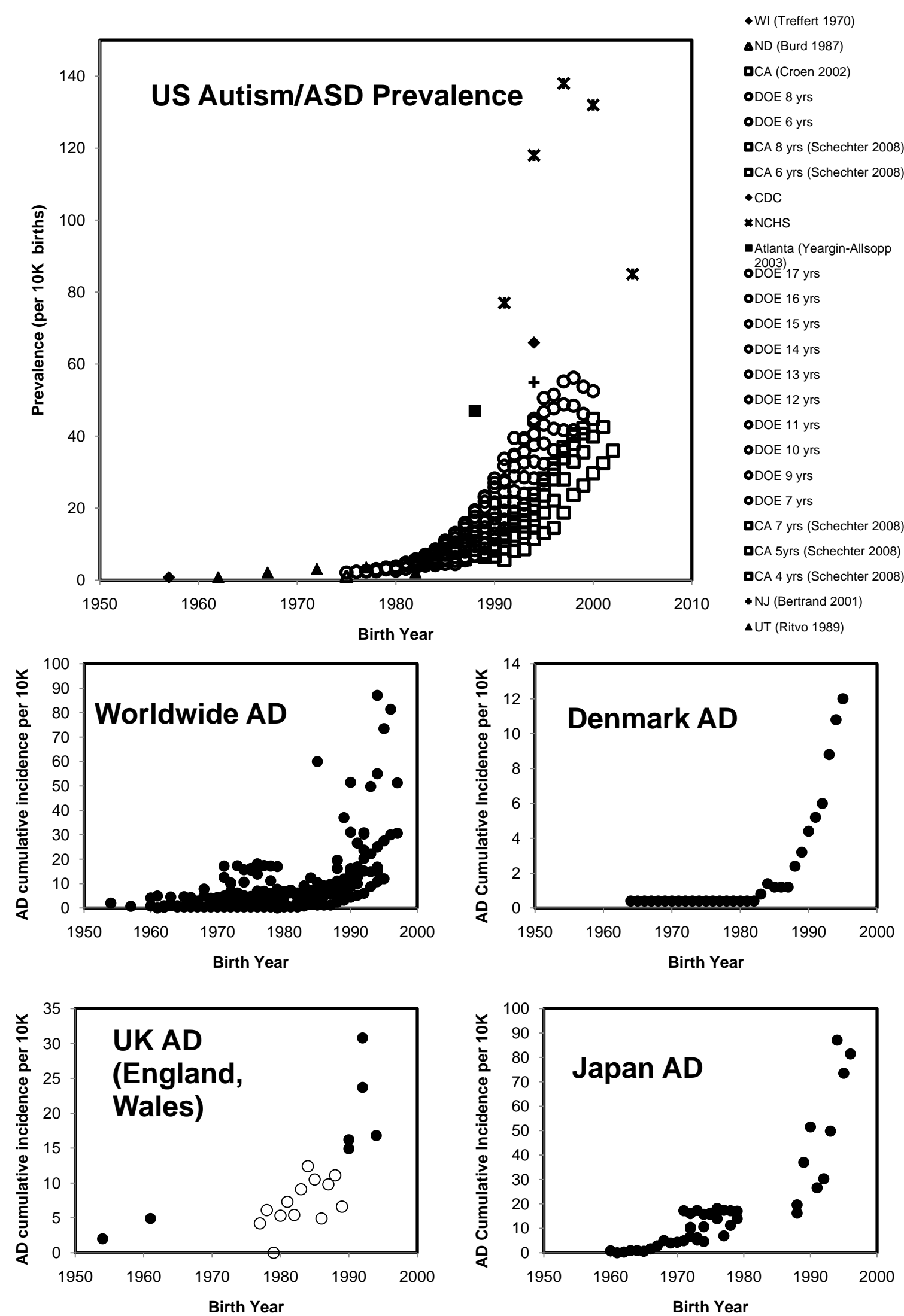


Quantitative Evaluation of Sociologic Factors That Can Lead to Apparent Increases in Autism Prevalence

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Introduction



In the US and other first world countries, autism has risen dramatically over the last 2-3 decades (see references 3, 4). Recent information suggest an autism increase within the last decade in Asian and African countries (e.g., Perera et al. 2009; Malhotra et al. 2005; Khan et al. 1996), although sample sizes are small. Scientific articles (e.g., Baron-Cohen 2009), popularly cited by the press, have characterized the measured rise in first world countries as being primarily artifactual, due to broadened diagnosis and improved ascertainment (increased awareness by professionals, increased awareness by parents, and increased special education funding).

Recent studies have shown that broadened diagnosis (MIND Institute 2002) and diagnostic substitution (e.g., Newschaffer et al. 2005, King & Bearman 2009) do not explain the measured increase in autism. A brief analysis of diagnostic coding changes and their relationship to autism disorder is shown in figure 3. Autism rates are commonly graphed by birth year, with diagnosis made between age 3 and 8. Therefore, diagnostic coding changes should first impact birth years 3-8 years prior to the year of diagnostic change (see Fig 3). Change-point analysis of California DDS data for AD identifies 1995 as an autism disorder change-point and no diagnostic relaxation event can be associated with this change-point (see poster 118.043).

The other factors (increased awareness by professionals and parents, increased funding), which are part of 'improved ascertainment' have not been objectively measured. In this study, we report the contributions of increased professional awareness, parental awareness, and federal special education funding to autism disorder prevalence using objective measures representative of these sociologic phenomena from publicly available data.

Methods

Autism Prevalence

State level data were obtained from various publications as listed in the references. US national prevalence data were downloaded from <http://www.fightingautism.org/idea/> and Department of Education. Some pre-computed prevalence data were verified with direct downloads from the Department of Education IDEA program (<http://www.ideadata.org>) and prevalence was obtained by normalizing to birthyear data as obtained from <http://www.cdc.gov/nchs>. Non-weighted averages are calculated if multiple prevalence measurements are shown for a given year.

Professional Awareness

The number of professionals who can diagnose autism and the number of professional publications on autism are used as objective measures of 'professional awareness'. Professional awareness can be quantitatively considered to be dependent both on the number of practicing professionals and on their interaction with other professionals, which can be measured using publication counts. It is assumed that all professionals read the literature, and the contents of their textbooks are ultimately derived from published scientific articles. Professionals who can diagnose ASD include pediatricians, psychiatrists, neurologists and clinical psychologists. The numbers of pediatricians, psychiatrists, and neurologists were obtained from the US Statistical Abstracts, (http://www.census.gov/compendia/statab/past_years.html) published by the US Census Bureau. The numbers of clinical psychologists were obtained from the Department of Labor (<http://www.dol.gov>); missing counts for some years were linearly extrapolated. Background population counts were also obtained from the US Statistical Abstracts. The number of professional publications on autism were obtained by searching PubMed (<http://www.ncbi.nlm.nih.gov/PubMed>) using search term "autism OR autistic" in the Title/Abstract. Only articles in English were used for comparisons with US data.

Parental Awareness

The number of messages on Yahoo groups related to autism is used to objectively measure parental awareness. Yahoo group websites (<http://groups.yahoo.com>) display the number of messages each month. These webpages were downloaded and parsed to obtain the numbers of messages per year. Only groups with 2 or more members were included. For comparison, the numbers of messages from Yahoo sites on 'Health and Wellness' and 'Children', but not on 'autism' or 'Asperger', were also obtained.

Federal Special Education Funding

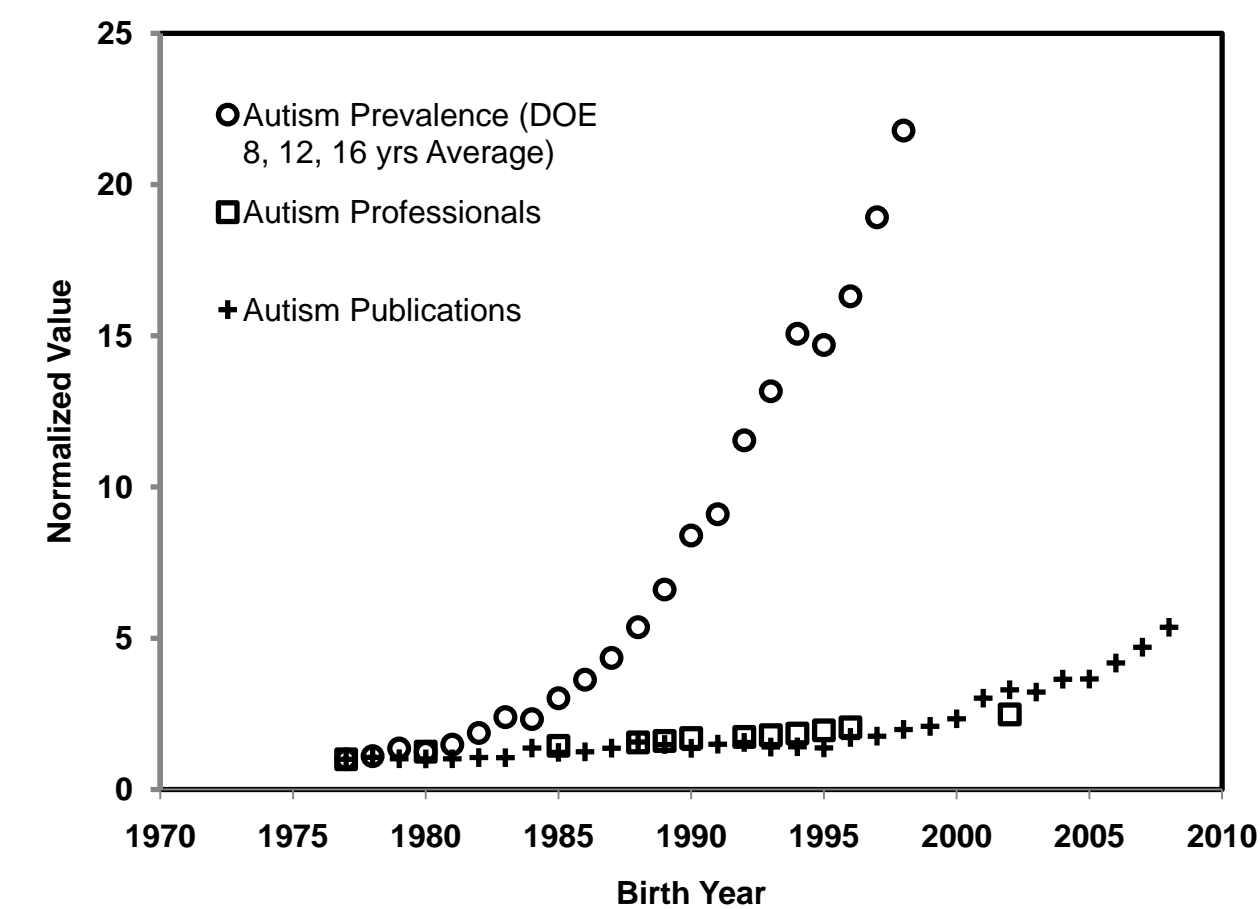
Funding tables were obtained from the CRS Report to Congress(2006) and the National Center for Education Statistics.

Input Data Statistics

| Data Source | Statistics |
|---------------------------------------|--|
| US Census, Dept. of Labor (1970-2002) | 128,000 average total of psychologists, psychiatrists, pediatricians, neurologists |
| Pubmed | 10,132 "autism OR autistic" articles (1977-2008); 10,689 for 1923-2008 14,288,181 total Pubmed articles for 1977-2008 |
| Yahoo (1990-2008) | 3,298 autism sites; 7,160,441 total messages 3,025 non-autism children's health sites; 3,126,315 total messages |

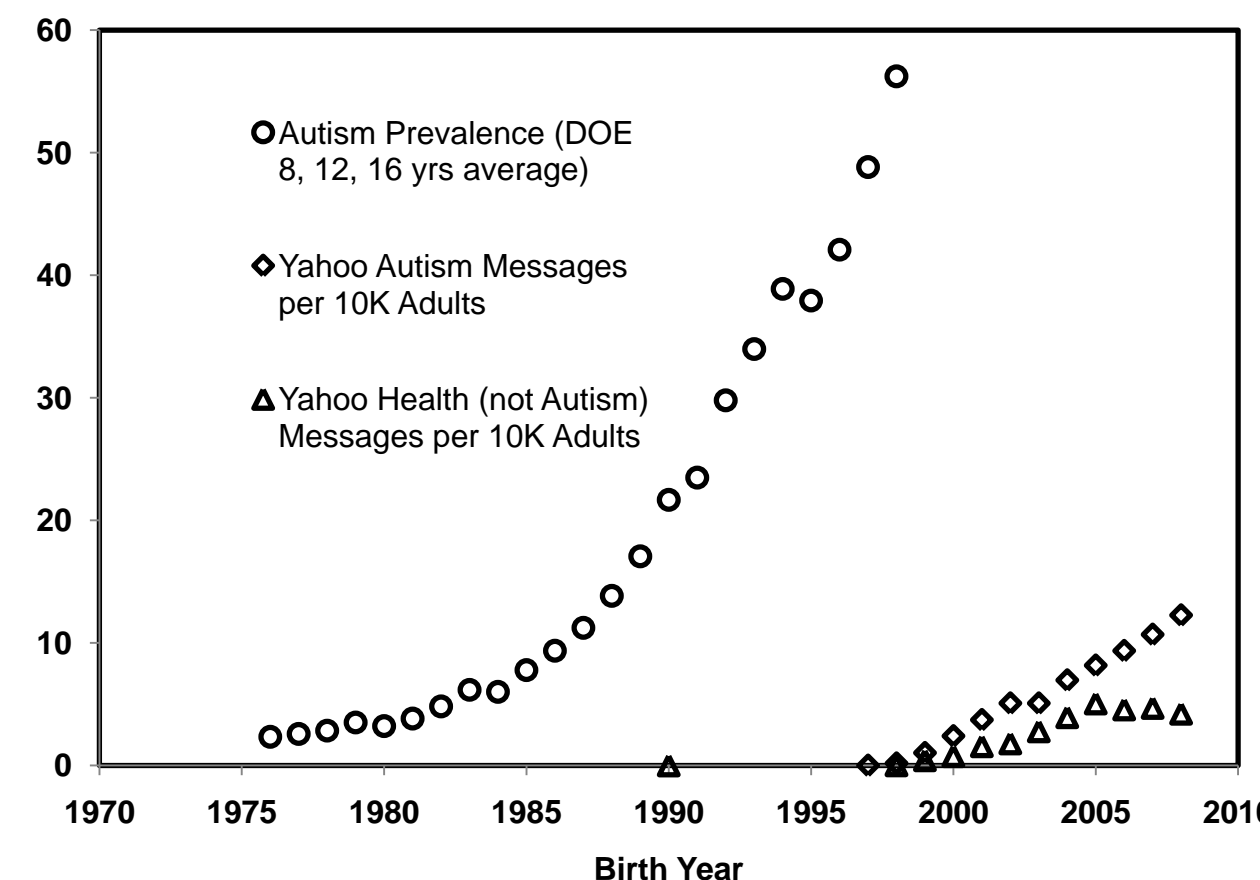
Results

Fig. 1 Comparison of Autism Prevalence, Number of Autism Professionals and Number of Autism Publications



Awareness of professionals increases much more slowly that the autism rate. Awareness increase also lags behind the autism increase. (Data normalized to 1977 values.)

Fig. 2 Comparison of Autism Prevalence Trends and Parent Interaction Trends



Increased awareness of parents, as measured by numbers of Yahoo chat group messages, do not play a significant role until the late 1990s.

Table 1

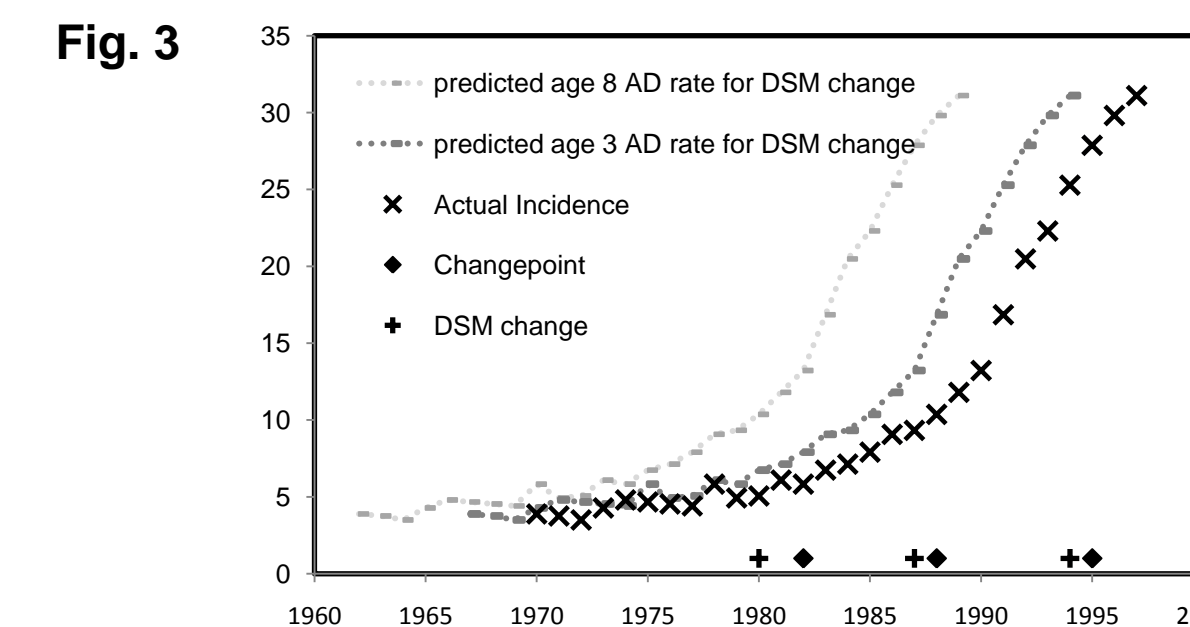
| Disability | 1976- | 1980- | 1990- | 1994- | 1995- | 1996- | 1997- | 1998- | 1999- | 2000- | 2001- | 2002- | 2003- | 2004- | 2005- | 2006- | |
|---|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-----|
| All disabilities | 8.3 | 10.1 | 11.4 | 12.2 | 12.4 | 12.6 | 12.8 | 13.0 | 13.2 | 13.3 | 13.4 | 13.5 | 13.7 | 13.8 | 13.7 | 13.6 | |
| Specific learning disabilities ¹ | 1.8 | 3.6 | 5.2 | 5.6 | 5.8 | 5.8 | 5.9 | 6.0 | 6.0 | 6.1 | 6.0 | 5.9 | 5.8 | 5.7 | 5.6 | 5.4 | |
| Speech or language impairments | 2.9 | 2.9 | 2.4 | 2.3 | 2.3 | 2.3 | 2.3 | 2.3 | 2.3 | 2.0 | 2.9 | 2.9 | 3.0 | 3.0 | 3.0 | 3.0 | |
| Mental retardation | 2.2 | 2.0 | 1.3 | 1.3 | 1.3 | 1.3 | 1.3 | 1.3 | 1.3 | 1.3 | 1.2 | 1.2 | 1.2 | 1.1 | 1.1 | 1.1 | |
| Emotional disturbance | 0.6 | 0.8 | 0.9 | 1.0 | 1.0 | 1.0 | 1.0 | 1.0 | 1.0 | 1.0 | 1.0 | 1.0 | 1.0 | 1.0 | 1.0 | 0.9 | |
| Hearing impairments | 0.2 | 0.2 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.2 | 0.2 | 0.2 | 0.2 | 0.2 | 0.2 | 0.2 | 0.2 | 0.2 | |
| Orthopedic impairments | 0.2 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.2 | 0.2 | 0.2 | 0.2 | 0.2 | 0.2 | 0.1 | 0.1 | |
| Other health impairments | 0.3 | 0.2 | 0.1 | 0.2 | 0.3 | 0.4 | 0.4 | 0.5 | 0.5 | 0.6 | 0.7 | 0.8 | 1.0 | 1.1 | 1.2 | 1.2 | |
| Visual impairments | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | |
| Multiple disabilities | — | 0.2 | 0.2 | 0.2 | 0.2 | 0.2 | 0.2 | 0.2 | 0.2 | 0.3 | 0.3 | 0.3 | 0.3 | 0.3 | 0.3 | 0.3 | |
| Deaf/blindness | — | — | — | — | — | — | — | — | — | — | — | — | — | — | — | — | |
| Autism | — | — | — | — | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.2 | 0.2 | 0.3 | 0.3 | 0.4 | 0.5 | 0.5 | |
| Traumatic brain injury | — | — | — | — | — | — | — | — | — | — | — | — | — | — | — | 0.0 | 0.1 |
| Developmental delay | — | — | — | — | — | — | — | — | — | 0.4 | 0.5 | 0.6 | 0.6 | 0.7 | 0.7 | 0.7 | |
| Preschool-age with disability ² | ↑ | ↑ | 0.9 | 1.2 | 1.2 | 1.2 | 1.2 | 1.2 | 1.2 | ↑ | ↑ | ↑ | ↑ | ↑ | ↑ | ↑ | |

Data from National Center for Health Statistics shows that disbursement of federal funding for autism (to be part of Special Education) did not start until 1995, even though legislation was signed in 1992.

Discussion

Autism prevalence is rising in the US and many other countries worldwide. The phrase 'improved ascertainment' has been used to explain and partially dismiss the significance of this rise. We quantified 'improved ascertainment' by using objective measures for the most important components of this term – professionals, parents, and funding.

Our results demonstrate that when objectively measured and analyzed, 'improved ascertainment' could not significantly contribute to the documented rise in AD or ASD prior to 1995. After 1995, both a linear increase in federal spending and an exponential increase in Internet use may have contributed to 'improved ascertainment'; however, the data also show that the rise in these measures occurs well after autism had already risen significantly. Therefore the increase in funding and internet awareness are more likely to be a result of, rather than the cause of, the rise in autism.



Summary

1. Autism prevalence increased much faster than increases in professionals or publications. In fact, the data suggest that increased awareness is caused by the increase in autism.
2. It was only after 1998 that parental awareness of autism increased significantly; however, much of this rise may be due to an expected increase due to Internet usage.
3. Although federal mandates for Special Education funding for autism were signed in 1992, funding did not get disbursed until 1995.
4. Although recent autism prevalence increases may be partly due to sociological reasons, there already existed a non-sociological rise before 1995.

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