

EPIDEMIOLOGY OF AUTISM

Past and future perspectives in autism epidemiology

Molecular Psychiatry (2002) 7, S9–S11. doi:10.1038/sj.mp.4001164

There have been three large autism prevalence reviews^{1–3} (Table 1). Four early studies (Table 1^{a–d}) used Kanner's criteria to characterize children with classic autism. The first population-based study reported a prevalence of 4.5 per 10 000; the other studies reported similar prevalence rates. Two studies used Rutter's criteria (Table 1^{e–f}), similar to Kanner's criteria, but the prevalence rates differed considerably (1.9 and 5.6 per 10 000 children). The *Diagnostic and Statistical Manual of Mental Disorders III (DSM-III)*⁴ first used the term Pervasive Developmental Disorders, which broadened the criteria, differentiating between autism and schizophrenia and describing onset as younger than 30 months. Studies using *DSM-III* criteria (Table 1^{g–o}) yielded rates of 3.3 (Table 1^g) to 16.0 (Table 1^h) per 10 000 children. Three studies (Table 1^{p–r}) using *DSM III-R*⁵ criteria reported rates of 10.1, 9.5, and 7.2 per 10 000 children. *DSM IV*⁶ and *International Classification of Diseases, Tenth Revision (ICD-10)*⁷ criteria are consistent; however recent studies using either criterion have yielded disparate prevalence rates.^{2–3}

Few studies exist of trends in autism prevalence. Studies of two French birth cohorts (1972 and 1976) documented no change in prevalence (5.1 and 4.9 per 10 000 children).⁸ In Sweden, autism prevalence increased from 4.0 to 11.6 per 10 000 children from 1962–1976 to 1975–1984 (Table 1^q). The Swedish investigators noted that rates of autism in children with mild mental retardation (IQ 50–70) remained relatively stable, while the rates increased in children with severe mental retardation (IQ < 50) and in children with normal intelligence (IQ > 70). They posited that changes in overall prevalence are influenced by the ability to better identify children with autism with very low, as well as normal to high, functioning. Asperger's syndrome was reported to occur in 26 to 36 per 10 000 individuals.²

Only three prevalence studies were conducted in the United States before 1998, all of which reported low prevalence rates: one from North Dakota (Table 1^g, 3.3 per 10 000 children); another from Utah (Table 1ⁿ, 3.6 per 10 000 children, and a third from Arkansas,⁹ 4.0 per 10 000 children). The lower prevalence rates may be attributed to limited access to complete health and education records needed for epidemiologic studies.

Because of the lack of recent prevalence data for the United States, researchers have used service provider data in an attempt to approximate current prevalence and understand trends in autism. However, these data are limited because: (1) the diagnosis of autism has not been consistently applied over time; and (2) the numbers of individuals receiving services do not represent a true prevalence rate. In addition, service provider data depend upon other sources of services within a community and are community-specific for a range of factors. Data from the California Department of Developmental Services system (DSS; 1987 to 1998) indicate a 273% increase in the number of individuals receiving autism services (2778 to 10 360), whereas the number of individuals receiving services related to other developmental disabilities increased only 44%.¹⁰ During the same time period, the number of persons in whom other pervasive developmental disorders were diagnosed and who received DSS services increased 1966%. Also, in 1998, the individuals with autism were younger and higher functioning than those receiving services in 1987. US Department of Education data also indicate that the number of children with autism served under the Individuals with Disabilities Education Act (IDEA), Part B (children aged 3–21 years), increased from 4795 to about 53 000, a more than 550% increase in services to children aged 6–17 years from the 1991–1992 school year to the 1998–1999 school year.¹¹

Reviews of the prevalence studies indicate that several methodologic issues that affect prevalence must be considered when interpreting reported prevalence rates. They include the case definition used, the method of case identification, and the effect of migration upon the population being studied. We do not know whether the increase in autism prevalence is 'real' or whether recent reports of a possible increase are due to methodologic issues, greater awareness of the conditions, or better availability of services. However, there appear to be more children with autism today than in the past.

In 1998, CDC and the Agency for Toxic Substances and Disease Registry (ATSDR) were contacted by families in Brick Township, New Jersey, because of concerns about a perceived increased prevalence of autism and a possible environmental correlation.¹² CDC and ATSDR agreed to conduct an autism prevalence study and to investigate potential environmental exposures of concern. The Brick Township prevalence study was modeled after the ongoing Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), a system to monitor several developmental disabilities, including autism.

Correspondence: Dr M Yeargin-Allsopp, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia 30341, USA. E-mail: mxyll@CDC.GOV

Table 1 Summary of autism prevalence from epidemiologic studies

	<i>Author</i>	<i>Rate of typical autism/10 000 (95% CI)</i>	<i>No. children with autistic disorder</i>	<i>No. children in population</i>	<i>M/F ratio</i>	<i>IQ ≤70%</i>
Kanner's criteria	Lotter, 1996 ^a (England)	4.5** (3.1–6.2)	35	78 000	2.6	84***
	Brask, 1972 ^b (Denmark)	4.3 (2.6–6.6)	20	46 500	1.5	NR
	Wing & Gould, 1979 ^c (England)	4.9 (2.9–7.8)	17	34 700	16.0	70
	Hoshino <i>et al</i> , 1982 ^d (Japan)	2.3 (2.0–2.8)	142	234 039	8.9	NR
Rutter's criteria	Steinhausen <i>et al</i> , 1986 ^e (Germany)	1.9 (1.4–2.4)	52	279 616	2.3	44
	Bohman <i>et al</i> , 1983 ^f (Sweden)	5.6 (4.0–8.0)	39	69 000	1.6	NR
DSM-III criteria	Cialdella & Mammelle, 1989 ^g (France)	4.5 (3.4–5.6)	61	135 180	2.0	NR
	Ishii & Takahashii, 1983 ^h (Japan)	16.0** (12.1–20.8)	56	35 000	6.0	NR
	Gillberg, 1984 ⁱ (Sweden)	4.0** (3.0–5.2)	52	128 584	1.8	77***
	McCarthy <i>et al</i> , 1984 ^j (Ireland)	4.3** (2.6–6.2)	28	65 000	1.3	NR
	Matsuishi <i>et al</i> , 1987 ^k (Japan)	15.5 (11.6–20.4)	51	32 834	4.0	NR
	Burd <i>et al</i> , 1987 ^l (USA)	3.3** (2.5–4.2)	59	180 986	2.7	NR
	Tanoue <i>et al</i> , 1988 ^m (Japan)	13.8 (11.6–16.4)	132	95 394	4.1	NR
	Ritvo <i>et al</i> , 1989 ⁿ (USA)	3.6 (2.1–4.5)	66	184 822	NR	NR
	Sugiyama & Abe, 1989 ^o (Japan)	13.0 (7.4–19.5)	16	12 263	NR	38
	DSM III-R criteria	Bryson <i>et al</i> , 1988 ^p (Canada)	10.1 (6.2–15.4)	21	20 800	2.5
Gillberg <i>et al</i> , 1991 ^q (Sweden)		9.5 (7.4–11.2)	55	78 106	2.9	80***
Webb <i>et al</i> , 1997 ^r (UK)		7.2 (5.4–9.5)	53	73 300	6.6	NR
ICD-10 criteria	Baron-Cohen <i>et al</i> , 1996 ^s (UK)	6.3 (3.0–11.5)	10	16 000	NR	NR
	Honda <i>et al</i> , 1996 ^t (Japan)	21.1 (12.6–33.5)	18	8537	2.6	50
	Fombonne <i>et al</i> , 1997 ^u (France)	5.4 (4.6–6.2)	174	325 347	1.8	88
	Arvidsson <i>et al</i> , 1997 ^v (Sweden)	31.0** (11.6–68.4)	6	1941	4.5	100

(Continued)

Table 1 Continued

Author	Rate of typical autism/10 000 (95% CI)	No. children with autistic disorder	No. children in population	M/F ratio	IQ \leq 70%
Fombonne & du Mazaubrun, 1992 ^w (France)	4.9 (4.1–5.7)	154	274 816	2.1	87
Sponheim & Skejeldal 1998 ^x (Norway)	3.8 (1.9–5.1)	25	65 688	2.1	64
Kadesjo, Gillberg & Hagberg, 1999 ^y (Sweden)	60.0 (19.0–141.0)	5	826	*	60**
Baird <i>et al</i> , 2000 ^z (England)	30.8 (22.9–40.6)	50	16 235	4.5	40

* All children were boys. NR, not reported.

** Overall rate.

*** Children with classic autism, childhood autism, or autistic disorder.

The children in Brick Township were 3–10 years of age (total population of 3 to 10-year-old children: 8896) and were residents in 1998. The study consisted of case identification and case verification (clinical examinations, psychological examinations, and administration of the Autism Diagnostic Observation Schedule–Generic). Children were identified through public and private schools, psychiatric and medical facilities, individual clinicians, and parental referral. The medical and education records of children who were potential cases for the study were also reviewed.

The prevalence of autistic disorder was 40 per 10 000 children (95% confidence interval (CI): 28–56) and the prevalence for all autism spectrum disorders was 67 per 10 000 children (95% CI: 51–87). The prevalence of autism in Brick Township was higher than most previously published rates. However, current rates of autism in the United States are not available; a few recent studies from other countries found similar rates to Brick Township. Well-designed, population-based studies of autism from other communities throughout the United States are needed to interpret the Brick Township findings.

CDC's public health response to concerns about autism includes funding five states to conduct population-based surveillance for autism and other developmental disabilities (grants were awarded during CDC budget year 2000). The funded sites will use methods developed for MADDSP with modifications to reflect the unique characteristics of the funded sites. In addition to surveillance, the CDC public health model also includes etiologic studies. Etiologic studies, as well as surveillance are being planned as part of the Centers of Excellence for Autism and Other Developmental Disabilities Epidemiology, which are mandated by the Children's Health Act of 2000. Four centers will be funded in 2001.

In conclusion, the study of autism is an evolving

effort. Epidemiology is one tool that can be used to learn more about the causes of autism. We need more data on the prevalence of autism in the United States. We believe that recent attention to autism issues has the potential to help elucidate answers.

M Yeargin-Allsopp, MD
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention, Atlanta,
Georgia, USA

- 1 Wing L. *Eur Child Adolesc Psychiatry* 1993; **2**: 61–74.
- 2 Gillberg C, Wing L. *Acta Psychiatr Scand* 1999; **99**: 399–406.
- 3 Fombonne E. *Psychol Med* 1999; **29**: 769–786.
- 4 American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 3rd edn. APA: Washington DC, 1980.
- 5 American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, revised* 3rd edn. APA: Washington DC, 1987.
- 6 American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 4th edn. APA: Washington DC, 1994.
- 7 The World Health Organization. *The ICD-10 Classification of Mental and Behavioral Disorders: Diagnostic Criteria for Research*. World Health Organization: Geneva, 1993.
- 8 Fombonne E, du Mazaubrun C. *Soc Psychiatry Psychiatr Epidemiol* 1992; **27**: 203–210.
- 9 Kirby RS *et al*. *Developmental and Behavioral Pediatrics* 1995; **16**: 318–326.
- 10 Department of Developmental Services. Changes in the population with autism and pervasive developmental disorders in California's developmental services system: 1987–1998. A report to the legislature. California Department of Developmental Services: Sacramento CA, March 1999.
- 11 US Dept of Education. Number of children with autism served under IDEA, Part B, 1991–92 to 1998–99. US Department of Education, Office of Special Education Programs, Data Analysis System, data based on December 1, 1996 count.
- 12 Dept of Health and Human Services (US). ATSDR public health assessment: Brick Township investigation. Final report. Dept of Health and Human Services (US): Atlanta, GA, Agency for Toxic Substances and Disease Registry, April 2000.