— REVIEW ARTICLES —

Epidemiology of Pervasive Developmental Disorders

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ABSTRACT: This article reviews the results of 43 studies published since 1966 that provided estimates for the prevalence of pervasive developmental disorders (PDDs), including autistic disorder, Asperger disorder, PDD not otherwise specified, and childhood disintegrative disorder. The prevalence of autistic disorder has increased in recent surveys and current estimates of prevalence are around 20/10,000, whereas the prevalence for PDD not otherwise specified is around 30/10,000 in recent surveys. Prevalence of Asperger disorder is much lower than that for autistic disorder and childhood disintegrative disorder is a very rare disorder with a prevalence of about 2/100,000. Combined all together, recent studies that have examined the whole spectrum of PDDs have consistently provided estimates in the 60–70/10,000 range, making PDD one of the most frequent childhood neurodevelopmental disorders. The meaning of the increase in prevalence in recent decades is reviewed. There is evidence that the broadening of the concept, the expansion of diagnostic criteria, the development of services, and improved awareness of the condition have played a major role in explaining this increase, although it cannot be ruled out that other factors might have also contributed to that trend. (*Pediatr Res* 65: 591–598, 2009)

This article provides an up-to-date review of methodological features and substantive results of published epidemiologic surveys of pervasive developmental disorders (PDD). PDDs are also sometimes referred to as autism spectrum disorders, and represent a class of disorders sharing similar features and including distinct diagnoses: autistic disorder, Asperger syndrome (AS), PDD not otherwise specified (PDDNOS), and childhood disintegrative disorder (CDD). Throughout, the term PDD refers to the broad class of disorders comprising all three specific diagnoses. This review updates previous reviews (1,2) with the inclusion of newly published surveys in the last 3 years. The specific questions addressed in this review are a) what is the range of prevalence estimates for autism and related PDDs? and; b) is the incidence of PDD increasing?

Selection of Studies

The studies were identified through systematic searches from the major scientific literature databases (MEDLINE, PSYCINFO) using search words "autism," "PDD," "epidemiology," "prevalence," and from prior reviews (1,2). Only studies published in the English language were included. Overall, 53 studies published between 1966 and 2008 were selected, which surveyed PDDs in clearly demarcated, non-overlapping samples. Of these, 43 studies provided information on the prevalence of autistic disorder and 19 studies provided estimates on the prevalence of all PDDs combined.

Survey Descriptions

Surveys were conducted in 17 countries and over half of the results have been published since 2000. Details on the precise sociodemographic composition and economical activities of the area surveyed in each study were not always available; most studies were, however, conducted in predominantly urban areas. The age range of the population included in the surveys is spread from birth to early adult life but most surveys have included school-age samples with an overall median age of 8.0. There was a huge variation in the size of the population surveyed. Studies with small sample sizes tended to yield higher prevalence than studies with larger sample sizes (2).

Study Designs

Some studies have relied on existing administrative databases (3–5) or on national registers (6) for case identification. Most investigations have relied on a two-stage or multistage approach to identify cases in underlying populations. The first screening stage of these studies often consisted of sending letters or brief screening scales requesting school and health professionals to identify possible cases of autism. Each investigation varied in several key aspects of this screening stage. First, the coverage of the population varied enormously from one study to another. In addition, the surveyed areas varied in terms of service development as a function of the specific

Abbreviations: ADI-R, Autism Diagnostic Interview—Revised; **AS,** Asperger Syndrome; **CARS,** Childhood Autism Rating Scale; **CDD,** childhood disintegrative disorder; **CDER,** Client Development and Evaluation Report; **DSM-IV,** Diagnostic and Statistical Manual, 4th Edition; **DSM-III,** Diagnostic and Statistical Manual, 3rd Edition; **DSM-III-R,** Diagnostic and Statistical Manual, 3rd Edition—Revised; **ICD-10,** International Classification of Diseases, 10th Edition; **PDD,** pervasive developmental disorder; **PDDNOS,** pervasive developmental disorder not otherwise specified; **RDC,** Research Diagnostic Criteria

educational or health care systems of each country and of the year of investigation. Second, the type of information sent out to professionals invited to identify children varied from simple letters including a few clinical descriptors of autism-related symptoms or diagnostic checklists rephrased in nontechnical terms, to more systematic screening based on questionnaires or rating scales of known reliability and validity. Third, participation rates in the first screening stages were variable although refusal rates tended to be very low.

Few studies provided an estimate of the reliability of the screening procedure. The sensitivity of the screening methodology is also difficult to gauge in autism surveys, as the proportion of false negatives was usually not estimated. Prevalence estimates must, therefore, be seen as underestimates of "true" prevalence proportions.

Participation rates in second stage assessments were also generally high. The source of information used to determine caseness usually involved a combination of informants and data sources, with a direct assessment of the person with autism in about half of the studies. However, surveys of large populations (7,8) did not include a direct diagnostic assessment of subjects. Nevertheless, the methods developed by the Centers for Disease Controls for recent large surveys have been described in detail and rely on a multisource multi-informant screening of the population, abstraction of key developmental data, and review by panels of expert clinicians who apply best-estimate procedures of known reliability and validity (7,8).

The assessments were conducted with various diagnostic instruments, ranging from a classical clinical examination to the use of batteries of standardized measures that included, in the most recent studies, gold standard diagnostic tools such as the Autism Diagnostic Interview-Revised (ADI-R) or the Autism Diagnostic Observational Schedule (ADOS). The precise diagnostic criteria retained to define caseness varied according to the study and, to a large extent, reflected historical changes in classification systems. Thus, Kanner's criteria, Lotter's, and Rutter's definitions were used in surveys conducted before 1980, whereas DSM-based definitions took over thereafter as well as ICD-10 since 1990. Kielinen *et al.* (9) have shown that a 2- to 3-fold variation in prevalence of autism can result from applying different diagnostic criteria to the same survey data.

Prevalence Estimations

Autistic disorder. Data on children with autistic disorder were available in 43 surveys (Table 1). The mean male:female ratio was 4.2:1. Prevalence estimates ranged from 0.7/10,000 to 72.6/10,000 (Table 1; 3,5,6,9,10–48). Prevalence was negatively correlated with sample size, and small-scale studies tended to report higher prevalence proportions. The correlation between prevalence and year of publication was statistically significant and studies with prevalence more than 7/10,000 were all published since 1987. These findings point toward an increase in prevalence estimates in the last 15–20 years. The interpretation of this trend is discussed below. In 18 studies published since 2000, the prevalence proportion

ranged from 7.2 to 40.5/10,000. The average prevalence was 20.6/10,000, a value that can be used as the best current estimate for the prevalence of autistic disorder.

Unspecified PDDs—PDDNOS. Several studies have provided useful information on rates of syndromes similar to autism but falling short of strict diagnostic criteria for autistic disorder (1,2). Different labels have been used to characterize them such as "autistic-like" disorders or the triad of impairments involving impairments in reciprocal social interaction, communication, and imagination (49) that would correspond to current diagnostic labels such as atypical autism and PDD-NOS. Seventeen of the 43 surveys yielded separate estimates of the prevalence of these atypical autistic syndromes, with 14 studies showing higher prevalence for the nonautism disorders than that for autism. The ratio of the prevalence of nonautistic PDD to the prevalence of autism had a mean value of 1.8, which, assuming a 20.6/10,000 prevalence for autistic disorder, translates into an average prevalence estimate of 37.1/10,000 for PDDNOS. This group has been much less studied in previous epidemiologic studies but progressive recognition of its importance and relevance to autism has led to changes in the design of more recent epidemiologic surveys (see below) that are now designed to include these less typical forms in their case definition. It should be clear from these figures that they represent a very substantial group of children whose treatment needs are likely to be as important as those of children with autism.

AS and childhood disintegrative disorder. Epidemiologic studies of AS are sparse, probably due to the fact that it was acknowledged as a separate diagnostic category only recently in both ICD-10 and DSM-IV. Only two epidemiologic surveys have been conducted, which *specifically* investigated its prevalence (34,50). However, only a handful ($n < 5$) of cases were identified in these surveys, with the resulting estimates being extremely imprecise. By contrast, other recent autism surveys have consistently identified smaller numbers of children with AS than those with autism *within* the same survey. In nine of 10 such surveys, the ratio of autism to AS prevalence in each survey was above unity, suggesting that the prevalence of AS was consistently *lower* than that for autism (Table 2; 5,32–36,40,42,45,48). How much lower is difficult to establish from existing data, but a ratio of 3 or 4 to 1 would appear an acceptable, albeit conservative, conclusion based on this limited available evidence. This translates into a prevalence proportion for AS, which would be ⅓ to ¼ that of autism. We, therefore, used for subsequent calculations an estimate of 6/10,000 for AS, recognizing the strong limitations of available data on AS.

Eight surveys provided data on CDD (51). Prevalence estimates ranged from 0 to 9.2/100,000. The pooled estimate based on eight identified cases and a total surveyed population of 406,660 children, was 2.0/100,000. The upper-bound limit of the associated confidence interval (4.0/100,000) indicates that CDD is a very rare condition, with about one case to occur for every 103 cases of autistic disorder.

Prevalence for combined PDDs. Taking the aforementioned estimates, the prevalence for all PDDs is estimated to be 63.7/

10,000 (*i.e.*, the sum of estimates for autism (20.6/10,000), PDDNOS (37.1/10,000), and AS (6/10,000)). These calculations are, however, approximations and provide only an estimated value for the prevalence estimates. Recent epidemiologic surveys that have focused on PDD as the case definition, yielded similar results with even higher values in several studies (Table 3; 4–8,35,37,40,42,45,46,48,52–58). The median prevalence of 19 studies in Table 3 is 63.5/10,000. The more recent CDC surveys (7,8) have confirmed slightly higher prevalence for the United States. In these studies, the case definition chosen was that of a PDD as opposed to the narrower approach focusing on autistic disorder that was typical of previous surveys. Investigators were concerned with any combination of severe developmental abnormalities occurring in one or more of the three symptomatic domains defining PDD and autism. Case finding techniques were proactive, relying on multiple and repeated screening phases, involving both different informants at each phase and surveying the same cohorts at different ages, which certainly maximized the sensitivity of case identification. In several studies, assessments were performed with standardized diagnostic measures (*i.e.*, ADI-R and ADOS), which match well the more dimensional approach retained for case definition. Conducted in different regions and countries by different teams, the convergence of estimates around 60 to 70 per 10,000 for all PDD combined is striking especially when coming from studies with improved methodology, and it represents the best estimate for the prevalence of PDDs currently available. This prevalence roughly translates into one child of 150 suffering from a PDD. However, some studies have reported prevalence proportions that are two to three times higher (46,58).

Is There An Autism Epidemic?

To examine the hypothesis of a secular increase in the prevalence of autism, it is crucial to differentiate prevalence (the proportion of individuals in a population who suffer from a defined disorder) from incidence (the number of new cases occurring in a population over a period of time). Both prevalence and incidence estimates will be inflated when case definition is broadened and case ascertainment is improved. Time trends in prevalence or incidence can, therefore, only be gauged in investigations that hold these parameters under strict control over time. These methodological requirements must be borne in mind while reviewing the evidence for a secular increase in the prevalence of PDDs.

Five approaches to assess this question have been used in the literature.

Referral statistics. Increasing numbers of children referred to specialist services or known to special education registers have been taken as evidence for an increased incidence of autism-spectrum disorders. However, trends over time in *referred* samples are confounded by many factors such as referral patterns, availability of services, heightened public awareness, decreasing age at diagnosis, and changes over time in diagnostic concepts and practices, to name only a few. Failure to control for these confounding factors was obvious in some recent reports such as the widely quoted reports from California educational services.

(http://www.dds.ca.gov/Autism/docs/AutismReport2003.pdf, http://www.dds.ca.gov/Autism/docs/autism_report_1999.pdf).

Strong evidence of "diagnostic switching" was produced in California (59) and in all US states (60), indicating that a relatively high proportion of children previously diagnosed as having mental retardation were now identified as having a PDD diagnosis. Decreased age at diagnosis has also been shown to contribute to the rising numbers of children diagnosed with PDD (61). In the United Kingdom, Jick *et al*. (62) have shown that the incidence of specific developmental disorders (including language disorders) decreased by about the same amount that the incidence of diagnoses of autism increased in boys born from 1990 to 1997. A more recent UK study (63) has shown that up to 66% of adults previously diagnosed with developmental language disorders would meet diagnostic criteria for a broad definition of PDD. Overall, evidence from these referral statistics is very weak and proper epidemiologic studies are needed to assess secular changes in the incidence of a disorder.

Comparison of cross-sectional epidemiologic surveys. As shown earlier, epidemiologic surveys of autism each possess unique design features which could account almost entirely for between-studies variations in prevalence proportions, and time trends in the prevalence of autism are, therefore, difficult to gauge from published prevalence estimates. The significant correlation previously mentioned between prevalence and year of publication could merely reflect increased efficiency over time in case identification methods used in surveys as well as changes in diagnostic concepts and practices (9,30,39,60,63). In studies using capture-recapture methods, it is apparent that up to one third of prevalent cases may be missed by an ascertainment source, even in recently conducted studies (57). The most convincing evidence that method factors could account for most of the variability in published prevalence estimates comes from a direct comparison of eight recent surveys conducted in the United Kingdom and the United States (2). In each country, four surveys were conducted around the same year and with similar age groups. As there is no reason to expect huge between-area differences in prevalence, prevalence estimates should, therefore, be comparable within each country. However, there was a 6-fold variation in prevalence for UK surveys and a 14-fold variation in US figures. In each set of studies, high estimates derived from surveys where intensive population-based screening techniques were used, whereas lower prevalence proportions were obtained from studies relying on passive administrative methods for case finding. Because no passage of time was involved, the magnitude of these gradients in prevalence can only be attributed to differences in case identification methods across surveys. Even more convincing evidence comes from the large survey by the CDC on 408,000 US children aged 8 and born in 1994 (8) where an average prevalence of 66/10,000 was reported for 14 US states. However, there was more than a 3-fold variation in state-specific prevalence proportions that ranged from a low 33/10,000 for Alabama to a high of 106/10,000 in New Jersey. These substantial differences reflected ascertainment variability across sites in a study that was otherwise performed with

Table 1. *Prevalence surveys of autistic disorder*

Country	Area	Size of target population	Age	No. subjects with autism	Diagnostic criteria	% With normal IQ	Gender ratio (M:F)	Prevalence/10,000	95% CI	References
UK	Middlesex	78,000	8–10	32	Rating scale	15.6	2.6 (23/9)	4.1	2.7; 5.5	10
Denmark	Aarhus County	46,500	2–14	20	Clinical	—	1.4 (12/7)	4.3	2.4; 6.2	11
USA	Wisconsin	899,750	3–12	69	Kanner	—	3.06 (52/17)	0.7	0.6; 0.9	12
UK	Camberwell	25,000	5–14	17*	24 items rating scale of Lotter	30	16 (16/1)	4.8†	2.1; 7.5	13
Japan	Fukushima–Ken	609,848	0–18	142	Kanner's criteria	—	9.9 (129/13)	2.33	1.9; 2.7	14
Sweden	County of Västerbotten	69,000	0–20	39	Rutter criteria	20.5	1.6 (24/15)	5.6	3.9; 7.4	15
Ireland	East	65,000	8–10	28	Kanner	—	1.33 (16/12)	4.3	2.7; 5.9	16
Germany	West Berlin	279,616	0–14	52	Rutter	55.8	2.25 (36/16)	1.9	1.4; 2.4	17
USA	North Dakota	180,986	2–18	59	DSM-III	—	2.7 (43/16)	3.26	2.4; 4.1	18
Japan	Kurume City	32,834	4–12	51	DSM-III	—	4.7 (42/9)	15.5	11.3; 19.8	19
Japan	Southern Ibaraki	95,394	7	132	DSM-III	—	4.07 (106/26)	13.8	11.5; 16.2	20
Canada	Part of Nova–Scotia	20,800	6–14	21	New RDC	23.8	2.5 (15/6)	10.1	5.8; 14.4	21
Japan	Nagoya	12,263	3	16	DSM-III	—	—	13.0	6.7; 19.4	22
France	1 département (Rhône)	135,180	3–9	61	DSM-III like	—	2.3	4.5	3.4; 5.6	23
USA	Utah	769,620	3–27	241	DSM-III	34	3.73 (190/51)	2.47	2.1; 2.8	24
Sweden‡	South–West Gothenburg + Bohuslän County	78,106	4–13	74	DSM-III-R	18	2.7 (54/20)	9.5	7.3; 11.6	25
France	4 régions 14 départements	274,816	9 & 13	154	Clinical–ICD–10 like	13.3	2.1 (105/49)	4.9	4.1; 5.7	26
Indonesia	Yogyakarita (SE of Jakarta)	5,120	4–7	6	CARS	0	2.0 (4/2)	11.7	2.3; 21.1	27
Japan	Yokohama	8,537	5	18	ICD-10	50.0	2.6 (13.5)	21.08	11.4; 30.8	28
France	3 départements	325,347	8–16	174	Clinical ICD-10–like	12.1	1.81 (112/62)	5.35	4.6; 6.1	29
UK	South Glamorgan, Wales	73,301	3–15	53	DSM-III-R	—	6.57 (46/7)	7.2	5.3; 9.3	30
Sweden (West coast)	Mölnlycke	1,941	3–6	9	ICD-10	22.2	3.5 (7/2)	46.4	16.1; 76.6	31
Norway	Akershus County	65,688	3–14	34	ICD-10	47.1§	2.09 (23/11)	5.2	3.4; 6.9	32
UK	North Thames	490,000	0–16	427	ICD-10	—	—	8.7	7.9; 9.5	33
Sweden (Central)	Karlstad	826	6.7–7.7	6	DSM-III–R/ICD–10 Gillberg's criteria (Asperger syndrome)	50.0	5.0 (5/1)	72.6	14.7; 130.6	34
UK	South-East Thames	16,235		50	ICD-10	60	15.7 (47/3)	30.8	22.9; 40.6	35
UK	West Midlands	25,377		62	Clinical/ICD10/DSM-IV	—	—	7.8	5.8; 10.5	36
Finland	North (Oulu and Lapland)	152,732		187	ICD-8/ICD-9/ICD-10	49.8	4.12 (156/50)	12.2	10.5; 14.0	9
USA	Brick Township, New Jersey	8,896		36	DSM-IV	36.7	2.2 (25/11)	40.5	28.0; 56.0	37
UK	England and Wales	10,438	5–15	27	DSM-IV/ICD-10	55.5	8.0 (24/3)	26.1	16.2; 36.0	38
Iceland	Whole Island	43,153	5–14	57	Mostly ICD-10	15.8	4.2 (46/11)	13.2	9.8; 16.6	39
UK (Midlands)	Staffordshire	15,500	2.5–6.5	26	ICD10/DSM-IV	29.2	3.3 (20/6)	16.8	10.3; 23.2	40
Israel	Haifa	26,160	7–11	26	DSM-III-R/DSM-IV	—	4.2 (21/5)	10.0	6.6; 14.4	41
USA	California DDS	4,950,333	5–12	5,038	CDER « Full syndrome »	62.8‖	4.47 (4116/921)	11.0	10.7; 11.3	3
Denmark	National register	63,859	8	46	ICD-10	—	—	7.2	5.0–10.0	6
UK (Midlands)	Staffordshire	10,903	4–7	24	ICD-10/DSM-IV	33.3	3.8 (19/5)	22.0	14.4; 32.2	42
USA, Minnesota	Olmstead County	37,726	0–21	112	DSM-IV	—	—	29.7	24.0; 36.0	43
Japan‖	Yokohama	32,791	5	123	ICD-10	25.3	2.5 (70/27)	37.5	31.0; 45.0	44
Canada (Quebec)	Montreal island	27,749	5–17	60	DSM-IV	—	5.7 (51/9)	21.6	16.5; 27.8	5
Denmark	Faroe Islands	7,689	8–17	12	ICD-10 Gillberg criteria for AS	—	3.0 (9/3)	16.0	7.0; 25.0	45
UK	South Thames, London	56,946	9–10	81	ICD-10	47	8.3 (≈72/9)	38.9	29.9; 47.8	46
Portugal	Mainland and Azores	67,795	6–9	115	DSM-IV	17	2.9	16.7	14.0; 20.0	47
UK	Wales	39,220	0–17	50	Kanner	—	—	12.7	9;17.0	48

(Continued)

the same methods and at the same time, and in children born in the same year. Thus, no inference on trends in the incidence of PDDs can be derived from a simple comparison of prevalence estimates over time, since studies conducted at different periods are likely to differ even more with respect to their methodology.

Repeat surveys in defined geographical areas. Repeated surveys, using the same methodology and conducted in the same geographical area at different points in time, can poten-

tially yield useful information on time trends provided that methods are kept relatively constant. The Göteborg studies (25,64) provided three prevalence estimates, which increased over a short period of time. However, different age groups were included in each survey. Other factors such as improved detection among the mentally retarded, cases born to immigrant parents, change in local services, and a progressive broadening of the definition of autism over time were hypothesized by the authors to account for the trend (64). Similarly, studies conducted in Japan at different points in time in Toyota (58) and Yokohama (28,44) showed rises in prevalence that their authors interpreted as reflecting the effect of both improved population screening of preschoolers and of a broadening of diagnostic concepts and criteria.

Two separate surveys of children born 1992–1995 and 1996–1998 in Staffordshire in the United Kingdom (40) were performed with rigorously identical methods for case definition and case identification. The prevalence for combined PDDs was comparable and not statistically different in the two surveys (42), suggesting no upward trend in overall prevalence of PDDs during the studies time interval. In the two recent CDC surveys (7,8), the prevalence at six sites included in the 2000 and 2002 surveys remained constant at

Table 2. *Asperger syndrome (AS) in recent autism surveys*

Assessment					Autism		Asperger syndrome			
Size of population	Age group	Informants	Instruments	Diagnostic criteria	N	Prevalence/ 10,000	N	Prevalence/ 10,000	Autism/AS ratio	References
65,688	3–14	Parent Child	Parental Interview + direct observation, CARS, ABC	ICD–10	32	4.9	2	0.3	16.0	32
490,000	0–16	Record	Rating of all data available in child record	ICD–10	427	8.7	71	1.4	6.0	33
826	6.7–7.7	Child Parent Professional	ADI–R, Griffiths Scale or WISC, Asperger Syndrome Screening Questionnaire	DSM–III–R/ICD– 10 Gillberg's criteria (Asperger syndrome)	6	72.6	4	48.4	1.5	34
25,377	1–4.9	Records	ADI–R Available data	DSM–III–R DSM–IV ICD–10	54	—	16	—	3.4	36
16,235	7	Parents Child Other data	ADI–R Psychometry	ICD–10 DSM–IV	45	27.7	5	3.1	9.0	35
15,500	2.5–6.5	Child Parent Professional	ADI–R, 2 wk multidisciplinary assessment, Merrill–Palmer, WPPSI	ICD–10 DSM–IV	26	16.8	13	8.4	2.0	40
10,903	2.5–6.5	Child Parent Professional	ADI–R, 2 wk multidisciplinary assessment, Merrill–Palmer, WPPSI	ICD–10 DSM–IV	24	22.0	12	11.0	2.0	42
7,689	8–17	Parent Child Professional	DISCO, WISC–R, ASSQ	ICD–10 Gillberg AS criteria	21	28.0	20	26.0	1.1	45
27,749	5–17	School registry	Clinical	DSM–IV	60	21.6	28	10.1	2.1	5
39,220	0–17	?	Clinical	Kanner, Gillberg AS criteria	50	12.7	139	35.4	0.36	48

Table 3. *Newer epidemiological surveys of PDDs*

Country	Area	Size	Age	N	Diagnostic criteria	% With normal IQ	Gender ratio (M:F)	Prevalence/10,000	95% CI	References
UK	South East Thames	16,235	7	94	ICD–10	60%	15.7 (83:11)	57.9	46.8–70.9	35
USA	New Jersey	8,896	3–10	60	DSM–IV	51%	2.7 (44:16)	67.4	51.5–86.7*	37
UK	Stafford	15,500	4–7	96	ICD–10	74.2%	3.8 (77:20)	61.9	50.2–75.6	40
Denmark	National register	—	8	738	ICD–10	—	—	30.0	—	6
UK	Stafford	10,903	4–6	64	ICD–10	70.2%	6.1 (55:9)	58.7	45.2–74.9	42
UK	Cambridge	33,598	5–11	196	ICD–10	—	4.0 (—)	58.3*	50–67*	52
USA	Atlanta	289,456	3–10	987	DSM–IV	31.8%	4.0 (787:197)	34.0	32–36	53
USA	Minnesota	—	8–10	—	—	—	—	52.0† 66.0	—	4
UK	South Thames	56,946	9–10	158	ICD–10	45%	3.3 (121:37)	116.1	90.4–141.8	46
USA	6 states	187,761	8	1,252	DSM–IV–TR	38%–60%‡	2.8:5.5	67.0	—‡	7
USA	14 states	407,578	8	2,685	DSM–IV–TR	55.4%§	3.4:6.5	66.0	63–68	8
Denmark	Faroe Islands	7,689	8–17	41	DSM–IV, Gillberg's criteria	68.3%	5.8 (35:6)	53.3	36–70	45
Canada	Montreal	27,749	5–17	180	DSM–IV	—	4.8 (149:31)	64.9	55.8–75.0	5
China	Hong Kong	4,247,206	0–14	682	DSM–IV	30	6.6 (592:90)	16.1 (1986–2005) 30.0 (2005)	—	54
Australia	Barwon	≈54,000	2–17	177	DSM–IV	53.4%	8.3 (158:19)	39.2	—	55
USA	South Carolina‖	47,726	8	295	DSM–IV–TR	39.6%	3.1 (224:71)	62.0	56–70	56
UK	South Wales	39,220	0–17	240	ICD–10, DSM–IV, Kanner's and Gillberg's criteria	—	6.8 (—)	61.2	54–69*	48
UK	Scotland	134,661	0–15	443‖	ICD–10, DSMIV	—	7.0 (369:53)	44.2‖	39.5–48.9	57
Japan	Toyota	12,589	5–8	228	DSM–IV	66.4%	2.8 (168:60)	181.1	158.5–205.9*	58

‡ Specific values for % with normal IQ and confidence intervals are available for each state prevalence.
§ Average across 7 states.
‖ Estimated using a capture-recapture analysis, the number of cases used to calculate prevalence was estimated to be be 596.
* Calculated by the author.
¶ Children aged 8, born either in 2000 and 2002, and included in the two CDC multisite reports.
† These are the highest prevalences reported in this study of time trends. The prevalence in 10-year-olds is for the 1991 birth cohort, and that for 8-year-olds for the 1993 birth cohort. Both prevalences were calculated in the 2001–2002 school year.

four sites, and increased in two states (Georgia and West Virginia) most likely due to improved quality of survey methods at these sites.

Successive birth cohorts. In large surveys encompassing a wide age range, increasing prevalence among most recent birth cohorts could be interpreted as indicating a secular increase in the incidence of the disorder, provided that alternative explanations can confidently be ruled out. This analysis was used in two large French surveys (26,29). The surveys included birth cohorts from 1972 to 1985 (735,000 children, 389 of whom had autism), and, pooling the data of both surveys, age-specific prevalence showed no upward trend (29).

Several analyses of special educational disability in the United States (4,60) showed increased numbers of PDD children in schools, but the increase was not specific to autism. These analyses also showed a marked period effect that identified the early 1990s as the period where the prevalence estimates started to go up in all ages and birth cohorts, coinciding closely with the inclusion of PDDs in the federal Individual with Disabilities Educational Act (IDEA) funding and reporting mechanism in the United States.

Incidence studies. The few incidence studies showed an upward trend in incidence over short periods of time. In one of the largest study of 1410 subjects, there was a 10-fold increase in the rate of first recorded diagnoses of PDDs in United Kingdom general practice medical records from 1988–1992 to 2000–2001 (65). The increase was more marked for PDDs other than autism but the increase in autism was also obvious. However, none of these studies investigations could determine the impact of changes over time in diagnostic criteria, improved awareness and service availability on the upward trend. The same conclusions apply to other incidence studies (36,43,44,54).

As it stands now, the recent upward trend in estimates of *prevalence* cannot be directly attributed to an increase in the *incidence* of the disorder. There is good evidence that changes in diagnostic criteria, diagnostic substitution, changes in the policies for special education, and the increasing availability of services are responsible for the higher prevalence figures. Most of the existing epidemiologic data are inadequate to properly test hypotheses on changes in the incidence of autism in human populations. Accordingly, the possibility that a true increase in the incidence of PDDs has also contributed to the upward trend in prevalence estimates cannot and should not be ruled out based on available data.

CONCLUSION

Epidemiologic surveys of autism and PDDs have now been carried out in several countries. Methodological differences in case definition and case finding procedures make between survey comparisons difficult to perform. However, from recent studies, a best estimate of 60 to 70/10,000 (equivalences = 6 to 7/1,000; or 0.6 to 0.7%; or one child in about 150 children) can be confidently derived for the prevalence of autism spectrum disorders. The results of this review, that incorporates findings from very large scale studies such as those conducted by the Center for Disease Control, provide robust evidence that PDDs are much more common than previously thought. In addition, as illustrated in the CDC surveys that used the same methods in 16 US states in a defined birth cohort of American children, there are states where the prevalence was underestimated due to lower service development and lower sensitivity. Thus, the current estimates are only average figures and it may be expected that future prevalence proportions will be higher in future surveys. In some countries, and in some US states, recent prevalence estimates are above the 1% mark. Current evidence does not strongly support the hypothesis of a secular increase in the incidence of autism but power to detect time trends is seriously limited in existing datasets. Although it is clear that prevalence estimates have gone up over time, this increase most likely represents changes in the concepts, definitions, service availability, and awareness of autistic-spectrum disorders in both the lay and professional public. To assess whether the incidence has increased, method factors that account for an important proportion of the variability in prevalence must be tightly controlled. The possibility that a true change in the underlying incidence has contributed to higher prevalence figures remains, however, to be adequately tested.

Taking 60 and 70/10,000 as two working prevalence figures for the combination of all PDDs, and using population estimates for the United States of July 1, 2002, it can be estimated that between 486,000 and 567,000 subjects younger than 20 years suffer from a PDD in the United States. These figures carry straightforward implications for current and future needs in services and early educational intervention programs.

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