

Cumulative Incidence and Prevalence of
Childhood Autism in Children in Japan

日本における小児自閉症の累積発症率および有病率

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Summary

Background. An epidemiological survey of childhood autism as defined in ICD-10 Research Criteria was conducted in the northern part of Yokohama, Japan.

Method. The routine health checkup for 18-month-old children served as the initial mass-screening, and all facilities which provide child care services function to detect all cases with childhood autism and refer them to the Yokohama Rehabilitation Centre. Cumulative incidence of childhood autism up to 5 years of age among the birth cohort of 1988, and prevalence on 1 January 1994, among residents born in 1988 were estimated.

Results. Cumulative incidence and prevalence were 16.2 per 10,000 and 21.1 per 10,000, respectively. Children with high-functioning autism who had IQs of 70 and over constituted approximately half of all the children with childhood autism.

Conclusion. It was confirmed through better detection of high-functioning cases that childhood autism is more common than formerly estimated.

Introduction

A number of papers on the epidemiology of autism have been published since Lotter (1966), yet variations remain even in the most basic epidemiological data regarding such issues as frequency. The reasons for variations may be multifactorial, but the literature on the frequency of autism raises several methodological issues. In addition to often discussed issues regarding diagnostic criteria (Wing, 1993), other methodological issues formerly not mentioned must be considered.

First, two measures of frequency in epidemiological studies, i.e., incidence and prevalence, must be distinguished. Although there have been a number of studies on the prevalence of autism, there have been none on incidence, mainly because the time of onset is difficult to identify. For the purpose of future research on the aetiology of autism, however, exact calculations of incidence should be attempted.

Second, methodological issues in the initial screening should be considered. Studies on the prevalence of autism can be classified into three groups based on initial screening methods. There is a strong possibility that these studies have overlooked cases in the initial screening. In the first group of studies (Lotter, 1966; Wing & Gould, 1979; Gillberg et al, 1991), at the researchers' request, staff from a wide range of facilities conduct the initial screening, primarily using a screening schedule or interviews. These staff are usually not specialists in administering mass-screening tools, and their knowledge of autism varies. In the second group (Steinhausen et al, 1986; Tanoue et al, 1988; Fombonne & du Mazaubrun, 1992), the daily clinical system, in which a limited number of special facilities provide service for a restricted area, allows for registration of cases. This method relies on voluntary consultation so cases not brought to special facilities remain unregistered. One study using the third type of initial screening (Sugiyama & Abe, 1989) utilises a

routine health checkup for 18-month-old children as a tool for the mass-screening of autism. This screening method is the most refined of the three, because specialists administer the mass-screening instruments. The problem of unregistered cases, however, remains unresolved, because only cases identified as positive are registered; and a small number of children do not participate in the checkup. Moreover, it is controversial whether autism can be detected with reasonable certainty at 18 months of age (Baron-Cohen et al, 1992; Johnson et al, 1992), and the screening might fail to detect some cases, for example those with speech loss after 18 months of age (Kurita, 1985) or "late onset" autism (Volkmar & Cohen, 1989).

In this study, an attempt was made to resolve problems of diagnostic criteria, incidence and prevalence, and registration. First, this study was restricted to childhood autism as defined in Diagnostic Criteria for Research (DCR) of ICD-10 (Table 1; World Health Organization, 1993) to have as much direct comparability across studies as

possible and to achieve a reasonable degree of homogeneity among subjects, for research purposes (Rutter & Schopler, 1992). Also, the process of how the ICD-10 criteria were elicited was described in detail. Second, cumulative incidence up to age 5 was estimated so the ambiguity of time of onset need not be considered. Since onset of childhood autism occurs prior to age 3 and the course is chronic, even the mildest cases can be diagnosed, with cumulative incidence reaching a plateau by age 5. Third, to solve the initial screening problem, a new system was developed for detecting all cases including those involving children who do not participate or are false negative in the initial screening.

Method

Yokohama city has a population of 3,291,849 (January 1994) and is the second most populated city in Japan. The Yokohama Rehabilitation Centre (YRC) is in charge of promoting community-oriented

rehabilitation for handicapped citizens of Yokohama city. The YRC Child Psychiatry Unit offers interdisciplinary services for children with mental retardation, pervasive developmental disorders, and other disorders occurring in childhood. From 1987 to 1994, the Unit administered the northern part of Yokohama city, i.e. Kohoku and Midori Wards, the catchment area of this study. This area is about 120 km² in size, and in January 1994, the total population of this area was 773,339, of which 1.0% were immigrants from foreign countries. This area is mainly urban and three-quarters of the population work in service industries, general commerce, or manufacturing, according to the 1990 census (Statistics Bureau, Prime Minister's Office). All three public health centres (PHCs) in the area cooperate closely with YRC.

Health checkup for 18-month-old children

For the purpose of this study, mass screening for childhood autism in the form of health checkups

for infants and children was advantageous because it is conducted routinely in clinical settings in Yokohama city. The health checkups were established for 4-month-old, 18-month-old, and 3-year-old children by the Maternal and Child Health Law. The purpose is to promote health and early detection of diseases and disorders occurring in infancy or childhood. Since diagnosis of childhood autism is usually possible around 3 years of age, the health checkup for 3-year-olds functions as a screening tool. However, for the purpose of constructing a system of early detection and early intervention, the health checkup for 18-month-old children (HC-18m) functions as the initial screening tool. Health checkups can be given either by primary care paediatricians or by staff at PHCs in the community, but in Yokohama they are conducted primarily by staff at PHCs who are more experienced than primary care paediatricians in conducting mass-screening of disorders including childhood autism.

The HC-18m conducted at the PHCs in Yokohama consists of both interviews with caregivers, and

direct observation and examination by public health nurses. Interviews with caregivers include questions about development of motor function, language comprehension, speech, and social interaction. Public health nurses with special training in mass-screening methods conduct simple examinations on cognition and language comprehension through which they also observe behaviour of the children directly and examine their social interaction, communication skills, and interests.

Additionally, each PHC has follow-up activities to confirm whether the screened children should be referred to YRC. This involves observation of the children's behaviour at home by a public health nurse and at PHC weekly group activities for mothers and children, and a developmental assessment by a clinical psychologist in the PHCs. If the assessment requires more expertise than is offered at the PHC, a team of specialists from YRC consisting of a child psychiatrist, a clinical psychologist, and a social worker may be consulted at the "Joint-clinic" held once a month at each PHC. After these

follow-up activities, if the screened children are suspected of having disorders, they are referred to YRC. Thus, children suspected of having childhood autism are followed by specialists from the time they are 18 months old. This is a contribution to the research on cumulative incidence because the interval of 18 months between birth and the time of screening is both the maximum length of time allowable to minimise loss of cases in the birth cohort due to migration and the minimum allowable to maintain a sufficient degree of sensitivity.

Each year, around 10% of the participants in the HC-18m are identified with problems. After follow-up, 1 - 2% of participants suspected of having disorders, including childhood autism, are referred to YRC.

The participation rate in the HC-18m has reached approximately 90%. This rate is high enough to make mass-screening feasible but is unsatisfactory for complete capture.

The "fail-safe" system

Most cases with childhood autism are referred to YRC by PHCs through the HC-18m, but some children are false-negative or do not participate in the checkup. These children may be identified at the health checkup for 3-year-old children which functions as another mass-screening. They may also be referred from kindergartens and nursery schools, other medical clinics, and child guidance clinics. Communication between YRC and these facilities contributes to efforts toward complete detection and referral of children with childhood autism. This network is called the "Early Detection - Early Intervention Network." YRC maintains a support system for related facilities, e.g., the joint-clinics at PHCs and periodic supervision programmes for kindergarten teachers to increase expertise in detecting childhood autism.

Based on the prediction that some children may be identified as false negative in the HC-18m, the author have made use of the Early Detection - Early Intervention Network as a "fail-safe" system to

capture the false negative cases (Fig.1) and to enable YRC to achieve complete registration of cases with childhood autism by five years of age at the latest.

Diagnostic procedure at the YRC

The YRC Child Psychiatry Unit, an interdisciplinary team including child psychiatrists, clinical psychologists, speech therapists, social workers, and teaching staff, offers various programmes of treatment and education for all children with childhood autism from the severely retarded to high-functioning cases. On their first consultation to YRC, the children are diagnosed by a child psychiatrist according to Clinical Descriptions and Diagnostic Guidelines of ICD-10 (Table 2; World Health Organization, 1992), which can minimise undiagnosed cases in clinical practice (Rutter & Schopler, 1992). A definite diagnosis is often difficult to make at the first consultation because information is insufficient to determine if the

child has pervasive developmental disorders (PDDs) or what category of PDDs is appropriate. A definite diagnosis is reached after the child undergoes a medical examination, psychological assessment, and behavioural assessment in a 10-week semi-structured group programme held once a week. In each of the assessments, any behavioural episodes specific to childhood autism are observed and recorded by knowledgeable staff. Since there is no standardised Japanese observation schedule according to ICD-10 specifically, each episode is recorded in a semi-structured manner to collect as much information as possible. After these examinations and assessments, the child psychiatrist rediagnoses the children. Next, a treatment procedure and educational programme of either group therapy or individual sessions with clinical psychologists or speech therapists are offered. The child psychiatrist periodically monitors the children with the aid of staff records and rediagnoses them if necessary. If children under three years of age exhibit characteristics of PDDs as defined by ICD-10 guidelines, they are diagnosed

as possible cases of autism and introduced to a further programme of treatment and education; a definite diagnosis is usually made at three years of age. A definite diagnosis of childhood autism is possible by the age of five years even for children with the mildest symptoms.

Identification of cases

This study surveyed children born in 1988. Most of them participated in the HC-18m in either 1989 or 1990. The participation rates for these two years were 85.0% and 86.4%, respectively. In the catchment area, there was an epidemic of rubella from January to July of 1987, but no other epidemics in 1987 and 1988 which might have affected the epidemiological data of childhood autism in children born in 1988.

From the YRC patient list, the author selected all children born in 1988 who had once been diagnosed as having childhood autism or possible autism using ICD-10 guidelines, even if their diagnoses had been

changed by the time of the survey. This procedure was conducted in 1994 when all children born in 1988 reached five years of age and definite clinical diagnoses had already been made. Then, for children who had been diagnosed as having childhood autism using ICD-10 guidelines, two experienced child psychiatrists independently made final diagnoses according to the ICD-10 DCR (1993), which may exclude some children clinically diagnosed with childhood autism using the guidelines (Rutter & Schopler, 1992). Only cases diagnosed with childhood autism using ICD-10 DCR by both child psychiatrists were selected. Children diagnosed according to the criteria by either psychiatrist as having any PDDs other than childhood autism were excluded from this study. Intellectual levels were measured at age five by standardised tests in routine clinical settings.

Cumulative incidence up to five years of age

Selected cases include children born in 1988

in the catchment area, regardless of where they now live. The author identify this number as *A*. The birth cohort in the catchment area in 1988 was 9,240 (4,719 boys, 4,521 girls) according to Yokohama city population statistics. Thus, cumulative incidence of childhood autism up to age five is *A* divided by 9,240.

Prevalence

Selected cases include children born in 1988, regardless of birthplace, and who lived in the catchment area on 1 January 1994. The author identify this number as *B*. On 1 January 1994, the population of children born in 1988 in the catchment area was 8,537 (4,408 boys, 4,129 girls). Thus, prevalence of childhood autism on 1 January 1994 in the population of children born in 1988 is *B* divided by 8,537.

Results

Identification of children with childhood autism

In the patient list of YRC, the number of children born in 1988 in the catchment area who had once been diagnosed as having childhood autism or possibly having autism based on ICD-10 guidelines was 36 (26 boys, 10 girls). Eighteen of these (12 boys, six girls) had received definite clinical diagnoses of childhood autism using ICD-10 guidelines by age five. Both child psychiatrists excluded two boys and a girl based on reassignment to other categories of PDDs using ICD-10 DCR. As a result, the number of children having childhood autism, A, born in 1988 in the catchment area was 15 (10 boys, five girls).

Thirty-eight children (28 boys, 10 girls) born in 1988 who lived in the catchment area on 1 January 1994 had once been diagnosed as having childhood autism or possibly having autism using ICD-10 guidelines. Twenty-one of these (15 boys, six girls) had received definite clinical diagnoses

of childhood autism by the age of five based on ICD-10 guidelines. Of these, the same three children as in the birth cohort were excluded using ICD-10 DCR. As a result, 18 children with childhood autism (13 boys, five girls), *B*, were born in 1988 and lived in the catchment area on 1 January 1994. All children included in *A* and *B* were native Japanese.

Fourteen children (10 boys, four girls) were included in both *A* and *B*. Of the 15 children in *A*, a girl in the birth cohort had moved out of the catchment area before 1 January 1994. Three boys and a girl, who were born outside the catchment area, lived in the catchment area on 1 January 1994.

A rubella epidemic broke out in the catchment area between January and July of 1987, introducing the possibility that prenatal infection may have affected the frequency of childhood autism (Chess, 1971). Children born before June 1988 stood a greater chance of prenatal infection of rubella than those born in or after June 1988. Of the

children identified as having childhood autism, three boys were born before June; two (13.3%) in 15 in the birth cohort and one (25.0%) in four born outside the catchment area. This number is small enough to disregard the possibility that the rubella epidemic had increased the birth rate of children with childhood autism. In addition, none of the three boys had any symptoms of congenital rubella.

Cumulative incidence up to five years of age

Cumulative incidence of childhood autism up to age five in the birth cohort was 16.2 per 10,000. Cumulative incidence by sex was 21.2 per 10,000 in boys, and 11.1 per 10,000 in girls. The male : female ratio of cumulative incidence was 1.9 : 1. These results are shown in Table 3.

Prevalence

Prevalence of childhood autism on 1 January 1994 in the population of children born in 1988 was

21.1 per 10,000. Prevalence by sex was 29.5 per 10,000 in boys, and 12.1 per 10,000 in girls. The male : female ratio of the cases was 2.6 : 1. The male : female ratio, after adjustment had been made for the male : female ratio in the general population, was 2.4 : 1. These results are shown in Table 4.

Proportion of children with high-functioning autism

Cases of high-functioning autism with IQs of 70 or over as determined by the Tanaka-Binet Test (the standardised Japanese version of Stanford-Binet) were examined (Table 5). IQs were measured at the age of five years in all but one girl in the birth cohort who had moved away before January 1994 and who was included in the group with high-functioning autism because her IQ was 94 when she was tested at the age of four years.

Of the 15 children with childhood autism in the cumulative incidence survey, eight (53.3%) were high-functioning cases; six of 10 boys (60%) and two of five girls (40%).

Of the 18 children with childhood autism in the prevalence survey, nine (50%) were high-functioning cases; seven of 13 boys (53.8%) and two of five girls (40%).

When a boy with borderline intellectual functioning was excluded, the proportion of children with IQs of 85 or over in the cumulative incidence survey was 46.7% (seven in 15; 50% of boys, 40% of girls) and 44.4% (eight in 18; 46.2% of boys, 40% of girls) in the prevalence survey. There were two boys (13.3% of the total and 20% of boys in the cumulative incidence survey; 11.1% of the total and 15.4% of boys in the prevalence survey) with IQs of 100 or over. The highest IQ score was 108.

Discussion

Diagnostic process using ICD-10 DCR

This is the first epidemiological study of childhood autism to use ICD-10 DCR. The defined criteria were elicited through repetitive direct

observations by specialists and interviews with caregivers based on over 10 weeks of assessment, treatment and education programmes. This study is also comparable to studies using the DSM system, because the definition of childhood autism in ICD-10 is conceptually identical to that of autistic disorder in DSM-IV (American Psychiatric Association, 1994) as Volkmar et al (1994) described.

Cumulative incidence

This study is the first to report cumulative incidence of childhood autism. A measure of incidence is often more useful than prevalence but tends to be more difficult to capture in many disorders occurring in childhood (Stein & Susser, 1981). This is true for childhood autism, in that the time of onset is difficult to identify. Thus, researchers in earlier studies concerned themselves with prevalence only. In this study, ambiguity as to the time of onset was resolved using cumulative incidence up to five years of age among a specified

birth cohort. Cumulative incidence was lower than prevalence, because the number of children with childhood autism who had moved into the catchment area was higher than the number of those who had moved out by five years of age. If official services for children with childhood autism differ among cities, it is possible that parents of children having childhood autism choose to remain in areas which have special facilities where their children can receive adequate care. Consequently, prevalence may be higher in such an area.

Comprehensiveness of the initial screening

Since Lotter (1966), prevalence of childhood autism has been believed to be 2 to 5 per 10,000. Some studies, however, suggest higher prevalence. This study revealed very high cumulative incidence and the highest prevalence of all; given its comprehensiveness, its results are valid. One important factor to consider in regard to comprehensiveness is its relationship to population

size. Since childhood autism is a rare disorder, a large population is necessary for an epidemiological study. But if the population is too large, the number of overlooked cases may be high. Considerable effort is needed to solve this antinomy. In her review on prevalence studies of autism, Wing (1993) stated that there was no significant relationship between size of population and prevalence of autism. She did not describe, however, what statistical analyses were used.

The author analyzed all of the peer reviewed papers on prevalence of autism in English language journals and journals with English summaries which describe diagnostic criteria used and population size (Table 6). There were 18 published studies divided into two groups. One consisted of five studies with populations of less than 50,000, and the other consisted of 13 studies with populations of more than 50,000. In four out of five papers (80%) in the former group, prevalence was more than 10.0 per 10,000. In contrast, out of 13 papers in the latter group, there were only two (18.2%) in

which prevalence was more than 10.0 per 10,000. Statistical analysis revealed significance in the distribution of frequency ($p=0.044$, two-tailed, Fisher's exact probability test).

This analysis suggests that studies of populations of above 50,000 might be more likely to yield lower prevalence. In the present study, the population was around 9,000, smaller than all earlier studies, and the number of overlooked cases would presumably be minimal by virtue of the "fail-safe" system.

Questions may remain regarding whether a population of 9,000 is too small for an epidemiological study of childhood autism. My clinical impression, however, is that a population of this size is approaching the maximum for the Early Detection - Early Intervention Network to function effectively as a fail-safe measure. It would be important to conduct further surveys in different birth cohorts in this catchment area to confirm stability of the frequency data in this size of population.

The second factor to consider is the awareness

of childhood autism among staff in the initial screening process. In a series of studies in Göteborg, Sweden, prevalence of autism in a similar population increased from 4.0 per 10,000 in 1980 to 11.6 per 10,000 in 1984, and this was considered partly due to better detection as a result of increased awareness of autism through education of professionals (Gillberg et al, 1991). In the present study, our Early Detection - Early Intervention Network in daily clinical activities guaranteed increased awareness of childhood autism.

Implications of the high proportion of children with high-functioning autism

Another unexpected finding is the high proportion of children with high-functioning autism. High-functioning autism is considered to exist in about 20% of the entire population with childhood autism (Gillberg et al, 1991). This study suggests a far greater proportion; about half the children were high-functioning. It should particularly be

emphasised that the number of children with IQs of 85 or over was far more than predicted. Does this indicate better detection of high-functioning autism or a decrease of childhood autism with mental retardation? Because high-functioning cases are more difficult to detect, the former possibility seems reasonable. Let us assume that sensitivity to high-functioning autism is lower in the catchment area of the present study. If the number of children having childhood autism with mental retardation, i.e. seven in the birth cohort and nine in residents in 1994, were stable, and the proportion of high-functioning autism were 20%, then the total number of cases would be nine and 11, resulting in a cumulative incidence of 9.7 per 10,000 and a prevalence of 12.9 per 10,000. These figures are closer to 11.9, the mean of the five prevalence studies with a population smaller than 50,000 (Table 6). In other words, frequency data on childhood autism in the present study would have approximated the mean of the earlier studies that did not utilise the "fail-safe" system. Better

detection of covert high-functioning cases through a rigorous screening process supported by the "fail-safe" system can account for the high cumulative incidence and the highest prevalence in the present study.

Some specialists may think that cases are sometimes missed in the early diagnostic process due to lack of awareness of high-functioning autism (Tsai, 1992). Cox & Mesibov (1995) think there exists a probability of overdiagnosing cases with specific learning disabilities and underdiagnosing high-functioning autism within the school-age population in the United States. The present study proves the existence of more high-functioning cases with autism, and this is consistent with these clinical impressions.

Ehlers & Gillberg (1993) have reported a very high prevalence of at least 3.6 per 1,000 for Asperger syndrome. Although the criteria for Asperger syndrome are still controversial, high-functioning autism and Asperger syndrome are considered in close proximity to each other on the spectrum of

PDDs (Frith, 1991). The results of high-functioning autism in this study will promote further clinical research on PDDs accompanying normal intelligence.

Conclusions

There appear to be more children with childhood autism, especially high-functioning cases, than were formerly estimated.

The "fail-safe" system was initially constructed for purely clinical purposes as a community system of early detection and early intervention in children having developmental disorders. This study illustrates that for epidemiological data to be worth utilising in both aetiological research and planning of services, community-oriented systems of clinical research must be promoted.

Acknowledgments

This study was supported by a grant to the author from the Yasuda Life Welfare Foundation. The

author is grateful to Dr. Yasuo Shimizu, Ms. Kimiko Misumi, Ms. Miyuki Niimi, Dr. Yasuo Ohashi, Dr. Yoshibumi Nakane, and Dr. Masami Sasaki for their comments on an earlier version of the manuscript.

Clinical implications

- Prevalence of childhood autism is higher than formerly estimated.
- A high proportion of children with high-functioning autism was found using a rigorous methodology in the initial screening process.
- Community-oriented systems of clinical research based on epidemiological methods must be promoted for the purposes of both research on and planning of services for those with childhood autism.

Limitation

- It is not yet proven whether the size of the population in this study was most appropriate for epidemiological studies of childhood autism.

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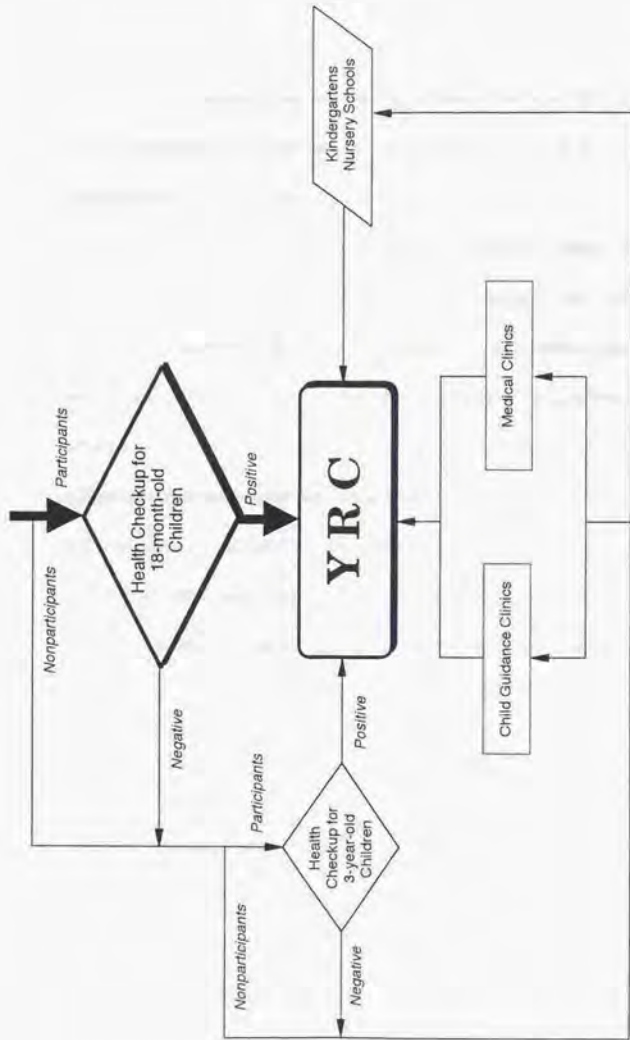


Fig.1

Legend for Fig.1

The Early Detection - Early Intervention Network in the catchment area as a "fail-safe" system for the screening of autism.

Children with childhood autism who do not participate or who are false negative in both health checkups might be taken for consultation to medical clinics or child guidance clinics, from where they are referred to YRC. The parents might also be encouraged by the staff of the kindergartens or nursery schools to consult YRC; many parents consult YRC on their own whenever they sense there might be developmental problems in their children.

Table 1
ICD-10 Diagnostic Criteria for childhood autism

F84.0 Childhood autism

A. Abnormal or impaired development is evident before the age of 3 years in at least one of the following areas:

- (1) receptive or expressive language as used in social communication;
- (2) the development of selective social attachments or of reciprocal social interaction;
- (3) functional or symbolic play.

B A total of at least six symptoms from (1), (2), and (3) must be present, with at least two from (1) and at least one from each of (2) and (3):

- (1) Qualitative abnormalities in reciprocal social interaction are manifest in at least two of the following areas:
 - (a) failure adequately to use eye-to-eye gaze, facial expression, body posture, and gesture to regulate social interaction;
 - (b) failure to develop (in a manner appropriate to mental age, and despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities, and emotions;
 - (c) lack of socio-emotional reciprocity as shown by an impaired or deviant response to other people's emotions; or lack of modulation of behaviour according to social context; or a weak integration of social, emotional, and communicative behaviours;
 - (d) lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. a lack of showing, bringing, or pointing out to other people objects of interest to the individual).

Table 1 *continued*

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- (2) Qualitative abnormalities in communication are manifest in at least one of the following areas:
- (a) a delay in, or total lack of, development of spoken language that is *not* accompanied by an attempt to compensate through the use of gesture or mime as an alternative mode of communication (often preceded by a lack of communicative babbling);
 - (b) relative failure to initiate or sustain conversational interchange (at whatever level of language skills is present), in which there is reciprocal responsiveness to the communications of the other person;
 - (c) stereotyped and repetitive use of language or idiosyncratic use of words or phrases;
 - (d) lack of varied spontaneous make-believe or (when young) social imitative play.
- (3) Restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities are manifest in at least one of the following areas:
- (a) an encompassing preoccupation with one or more stereotyped and restricted patterns of interest that are abnormal in content or focus; or one or more interests that are abnormal in their intensity and circumscribed nature though not in their content or focus;
 - (b) apparently compulsive adherence to specific, non-functional routines or rituals;
 - (c) stereotyped and repetitive motor mannerisms that involve either hand or finger flapping or twisting, or complex whole body movements;
 - (d) preoccupations with part-objects or non-functional elements of play materials (such as their odour, the feel of their surface, or the noise or vibration that they generate).
- C. The clinical picture is not attributable to the other varieties of pervasive developmental disorder: specific developmental disorder of receptive language (F80.2) with secondary socio-emotional problems; reactive attachment disorder (F94.1) or disinhibited attachment disorder (F94.2); mental retardation (F70 - F72) with some associated emotional or behavioural disorder; schizophrenia (F20.-) of unusually early onset; and Rett's syndrome (F84.2).
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World Health Organization (1993). *The ICD-10 Classification of Mental and Behavioural Disorders: Diagnostic Criteria for Research*, Geneva: WHO, pp.147-149.

Table 2
ICD-10 Clinical Descriptions and Diagnostic Guidelines for childhood autism

F84.0 Childhood autism

A pervasive developmental disorder defined by the presence of abnormal and / or impaired development that is manifest before the age of 3 years, and by the characteristic type of abnormal functioning in all three areas of social interaction, communication, and restricted, repetitive behaviour. The disorder occurs in boys three to four times more often than in girls.

Diagnostic guidelines

Usually there is no prior period of unequivocally normal development but, if there is, abnormalities become apparent before the age of 3 years. There are always qualitative impairments in reciprocal social interaction. These take the form of an inadequate appreciation of socio-emotional cues, as shown by a lack of responses to other people's emotions and / or a lack of modulation of behaviour according to social context; poor use of social signals and a weak integration of social, emotional, and communicative behaviours; and, especially, a lack of socio-emotional reciprocity. Similarly, qualitative impairments in communications are universal. These take the form of a lack of social usage of whatever language skills are present; impairment in make-believe and social imitative play; poor synchrony and lack of reciprocity in conversational interchange; poor flexibility in language expression and a relative lack of creativity and fantasy in thought processes; lack of emotional response to other people's verbal and nonverbal overtures; impaired use of variations in cadence or emphasis to reflect communicative modulation; and a similar lack of accompanying gesture to provide emphasis or aid meaning in spoken communication.

The condition is also characterized by restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities. These take the form of a tendency to impose rigidity and routine on a wide range of aspects of day-to-day functioning; this usually applies to novel activities as well as to familiar habits and play patterns. In early childhood particularly, there may be specific attachment to unusual, typically non-soft objects. The children may insist on the performance of particular routines in rituals of a nonfunctional character; there may be stereotyped preoccupations with interests such as dates, routes or timetables; often there are motor stereotypies; a specific interest in nonfunctional elements of objects (such as their smell or feel) is common; and there may be a resistance to changes in routine or in details of the personal environment (such as the movement of ornaments or furniture in the family home).

Table 2 continued

In addition to these specific diagnostic features, it is frequent for children with autism to show a range of other nonspecific problems such as fear / phobias, sleeping and eating disturbances, temper tantrums, and aggression. Self-injury (e.g. by wrist-biting) is fairly common, especially when there is associated severe mental retardation. Most individuals with autism lack spontaneity, initiative, and creativity in the organization of their leisure time and have difficulty applying conceptualizations in decision-making in work (even when the tasks themselves are well within their capacity). The specific manifestation of deficits characteristic of autism change as the children grow older, but the deficits continue into and through adult life with a broadly similar pattern of problems in socialization, communication, and interest patterns. Developmental abnormalities must have been present in the first 3 years for the diagnosis to be made, but the syndrome can be diagnosed in all age groups.

All levels of IQ can occur in association with autism, but there is significant mental retardation in some three-quarters of cases.

Includes: autistic disorder
infantile autism
infantile psychosis
Kanner's syndrome

Differential diagnosis. Apart from the other varieties of pervasive developmental disorder it is important to consider: specific developmental disorder of receptive language (F80.2) with secondary socio-emotional problems; reactive attachment disorder (F94.1) or disinhibited attachment disorder (F94.2); mental retardation (F70 - F79) with some associated emotional / behavioural disorder; schizophrenia (F20.-) of unusually early onset; and Rett's syndrome (F84.2).

Excludes: autistic psychopathy (F84.5)

World Health Organization (1992). The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines, Geneva: WHO, pp.253-254.

Table 3

Cumulative incidence of childhood autism up to
five years of age in the birth cohort of 1988

	Diagnosed cases	Birth cohort of 1988	Cumulative incidence per 10,000
Male	10	4,719	21.2
Female	5	4,521	11.1
Total	15	9,240	16.2

Table 4
Prevalence of childhood autism on 1 January 1994,
in the population of children born in 1988

	Diagnosed cases	Population of children born in 1988	Prevalence per 10,000
Male	13	4,408	29.5
Female	5	4,129	12.1
Total	18	8,537	21.1

Table 5

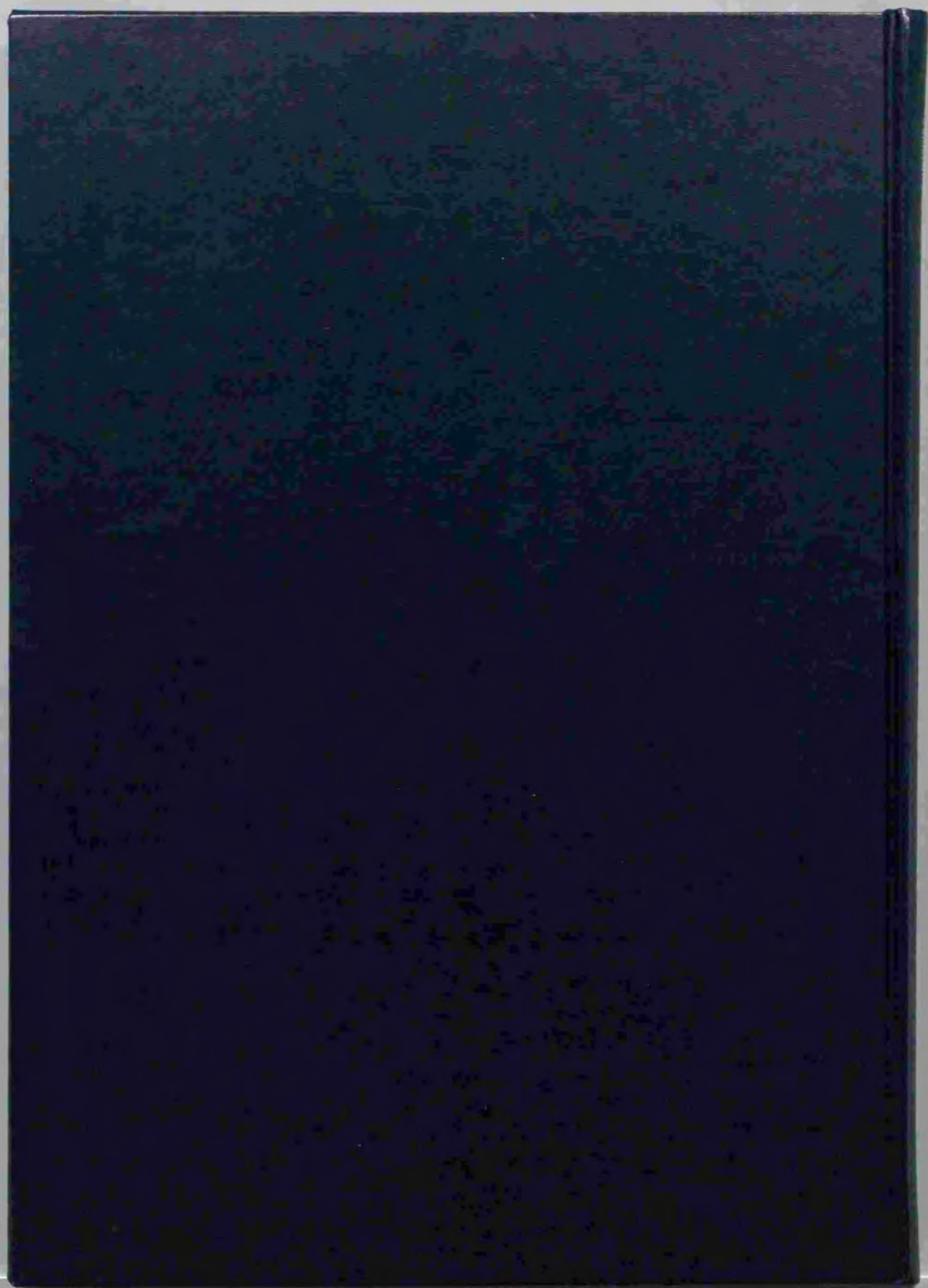
Intellectual levels of children with childhood autism born in 1988

IQ score	Cases born in the catchment area		Cases among residents on 1 January 1994	
	<i>n</i> (%)	Male:Female	<i>n</i> (%)	Male:Female
> 100	2 (13.3%)	2:0	2 (11.1%)	2:0
85 - 99	5 (33.3%)	3:2	6 (33.3%)	4:2
70 - 84	1 (6.7%)	1:0	1 (5.6%)	1:0
50 - 69	2 (13.3%)	1:1	2 (11.1%)	1:1
< 50	5 (33.3%)	3:2	7 (38.9%)	5:2
Total	15 (100%)	10:5	18 (100%)	13:5

Table 6
Results of earlier prevalence studies of autism by population size

Investigator	Year	Age range (years)	Total children in age range	Prevalence per 10,000 population
Population size smaller than 50,000				
Sugiyama & Abe	1989	3	12,263	13.0
Bryson <i>et al</i>	1988	6-14	20,800	10.1
Matsuishi <i>et al</i>	1987	4-12	32,834	15.5
Ishii & Takahashi	1983	6-12	34,987	16.0
Wing & Gould	1979	0-14	35,000	4.9
Population size larger than 50,000				
McCarthy <i>et al</i>	1984	8-10	65,000	4.3
Lotter	1966	8-10	78,000	4.5
Gillberg <i>et al</i>	1991	4-13	78,106	9.5
Steffenburg & Gillberg	1986	0-9	78,413	6.6
Tanoue <i>et al</i>	1988	7	95,394	13.8
Gillberg	1984	4-18	128,584	4.0
Cialdella & Mamelle	1989	5-9	135,180	10.8
Burd <i>et al</i>	1987	2-18	180,986	3.3
Ritvo <i>et al</i>	1989	8-12	184,822	3.6
Hoshino <i>et al</i>	1982	5-11	217,626	5.0
Fombonne & du Mazaubrun	1992	9&13	274,816	4.9
Steinhausen <i>et al</i>	1986	0-15	279,616	1.9
Treffert	1970	3-12	899,750	3.1

For more information about papers not referenced, see Wing (1993).



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