# Asperger Syndrome—Some Epidemiological Considerations: A Research Note

# I. Carina Gillberg\* and Christopher Gillberg\*

Abstract—Asperger syndrome has so far been the subject of very little systematic empirical inquiry. This paper reviews those few studies in the literature and some data from a new Swedish study which has reported findings pertinent to estimations of Asperger syndrome prevalence. It is concluded that among children with normal intelligence, rates of 10–26 per 10,000 children are minimum figures. Another 0.4 per 10,000 Swedish teenagers showed the combination of Asperger syndrome and mild mental retardation.

Keywords: Asperger's syndrome, epidemiology

#### Introduction

Several studies have examined the prevalence of the syndrome first described by Kanner (1943) and now variously referred to as "infantile autism", "autistic syndrome", or "autistic disorder" (Lotter, 1966; Wing & Gould, 1979; Gillberg, 1984; Steffenburg & Gillberg, 1986; Bryson, Clark & Smith, 1988).

Hans Asperger in 1944 described a group of children clearly resembling those described by Kanner. To this day, the controversy has not been resolved as to whether Kanner and Asperger syndromes are separate diagnostic entities or constitute different sections on a continuum of autistic spectrum disorders. Followers of the latter 'tradition' tend to view Asperger syndrome (Wing, 1981a; Schopler, 1985; Gillberg, 1985) as possibly a mild variant of autism in relatively bright children.

We are not aware of any published material reporting on the population prevalence in Asperger syndrome. Such a study is under way in this centre. We do already have some data relevant for the discussion of Asperger syndrome epidemiology, which go back to studies on children with deficits in attention, motor control and perception (DAMP) (Gillberg, 1983) and infantile autism (Gillberg, 1984; Steffenburg & Gillberg, 1986). Comparing these data with those of Lorna Wing and those of previous investigators in the field of autism, some tentative conclusions regarding the epidemiology of Asperger syndrome can be reached.

#### Accepted manuscript received 14 September 1988

<sup>\*</sup>Department of Child and Adolescent Psychiatry, University of Göteborg, Sweden.

Requests for reprints to: Professor C. Gillberg, Department of Child and Adolescent Psychiatry, Child Neuropsychiatry Centre, Box 17113, S-402 61, Göteborg, Sweden.

### Definition of Asperger syndrome

Asperger syndrome was diagnosed in cases showing all of the following six symptoms:

- (1) Severe impairment in reciprocal social interaction, showing in (a) inability to interact or play reciprocally with age-peers, (b) a lack of normal desire to be in the company of age-peers, (c) a lack of appreciation of social cues, resulting in odd, socially or emotionally inappropriate behaviour, usually thought to reflect "coldness", "stiffness", "emotional bluntness/immaturity", "extreme egocentricity" or "(unintentional) play acting" (such as in the movies from the early period).
- (2) An all-absorbing, circumscribed interest in a subject, such as meteorology, astronomy or Greek history. This interest may change in content over the years, but its fundamental style remains in that it goes to extremes, excludes most other activities and is adhered to in a repetitive way and relies on rote memory rather than meaning and connection.
- (3) A stereotyped way of trying to introduce and impose routines or the particular interest in all or almost all aspects of ordinary life.
- (4) Speech and language problems showing as (a) delayed language development as compared with expected given the child's social language background, (b) superficially perfect expressive language with a strong tendency to become formal and pedantic and usually with a flat, staccato-like prosody, and (c) mild or moderate impairment of language comprehension with concrete misinterpretations of spoken language against a background of much better expressive language skills.
- (5) Non-verbal communication problems, with limited or clumsy gestures and little or inappropriate facial expression.
- (6) Motor clumsiness was not a prerequisite for diagnosis of Asperger syndrome in a previous publication from this centre (Gillberg, 1988). However, as it turned out, almost all of the 23 children in that study were found to suffer from overall clumsiness on neurodevelopmental examination. We therefore decided to include it in our diagnostic definition of Asperger syndrome.

No requirements were imposed regarding the child's intellectual level.

This definition of Asperger syndrome is in good accord with the descriptions given by Asperger himself (1944) and also with that of van Krevelen (1971) and Lorna Wing (1981a). However, neither Asperger nor Wing has detailed specific criteria, and they both refer to partial or spectrum cases. Furthermore, the criteria outlined here share features of defining symptoms of "autistic disorder" and "infantile autism". The criteria are used for the purpose of estimating the scope of the problem of Asperger syndrome, and it is hoped that they will not be used in order to inflate the ongoing debate about whether or not Kanner and Asperger syndromes are clearly different entities.

# Population-based study of DAMP in Göteborg

In a population-based study of 6-yr-old children performed in Göteborg in 1977, we found 1.2% of the whole non-mentally retarded population to suffer from the combination of severe motor clumsiness (though not fulfilling criteria for cerebral

palsy) and attention deficit disorder (Gillberg, Rasmussen, Carlström, Svenson & Waldenström, 1982). This group in our study was represented by 14 individuals (11 girls, three boys). Another 10% of the population showed motor clumsiness without attention deficit disorder. This latter group was respresented by only seven individuals (four girls, three boys) in our study.

These children, and a comparison group of 51 children, were examined by two child psychiatrists who were independent and blind as to group status at age 7 yrs.

Operational criteria for "psychotic behaviour" (Gillberg, 1983) or "autistic type traits" had been outlined beforehand. They comprised the combination of (1) disturbance in the field of social relationships (particularly a reduction in the capacity for reciprocal interaction with age-peers), (2) disturbance of speech and language showing as "immaturities", age-inappropriate levels of echolalia or restricted, formalistic language, and (3) stereotyped behaviours or interests.

Altogether, eight children showed such "autistic type traits". All were found in the group with concomitant severe motor clumsiness and attention deficit disorder. Of these eight, one actually fulfilled DSM-III-R criteria (1987) for autistic disorder. The remaining seven cases were re-analysed for the purpose of the present report. Three (all boys) were found who fulfilled all the six criteria for Asperger syndrome. The other four children fulfilled three, three, four and four criteria, respectively.

The original group of 14 children from which these Asperger cases were drawn corresponded to 1.2% of the whole population (see above). The three Asperger syndrome cases represent 0.26% of the age-population.

Considering our selection criteria, the frequency we found has to be a minimum one. For instance, the mentally retarded population was withdrawn from the study. Also, even though we included motor clumsiness as a necessary criterion for a diagnosis of Asperger syndrome, the fact that our screening was not primarily geared to finding children with social deficits makes for uncertainty as regards the true prevalence of problems in that field. Thus, on the basis of the results obtained in this study, originally designed to study problems associated with DAMP, a minimum prevalence for Asperger syndrome among 7-yr-old children without clear-cut mental retardation would be 26 in 10,000.

Follow-up at ages 10, 13 and 16 yrs (e.g. I. C. Gillberg, 1987) has shown these three children diagnosed as having Asperger syndrome at age 7 yrs to have a relatively stable personality structure, with typical Asperger type handicaps and characteristics persisting well into the teens at least.

# Population-based study of mental retardation in Göteborg

In a population-based study of 13-17-yr-olds in Göteborg performed in 1984, we found 0.4% of the whole population to have mild mental retardation (IQ 50-70) and 0.3% to have severe mental retardation (IQ  $\leq$  50) (Hagberg, Hagberg, Lewerth & Lindberg, 1981). In the severely retarded groups, no one case fulfilled criteria for Asperger syndrome. However, one boy in the mildly mentally retarded group did fulfil such criteria. This corresponds to 0.004% of the population. This study was very thorough and almost every single child (n = 149) with mental retardation was

clinically/psychiatrically examined (Gillberg, Persson, Grufman & Temnér, 1986). Asperger syndrome as outlined in this context was specifically looked for. Therefore, the figure of 0.4 per 10,000 of the whole population of urban 13–17-yr-olds suffering from Asperger syndrome and mild mental retardation appears to be close to the true prevalence.

# Population-based study of severe social impairment in Göteborg normal schools

In 1985, a remedial education teacher with long-term experience from a special school for children with severe social impairments (on the autism spectrum) screened all normal schools (attended by 99% of the whole school-age population), covering virtually all children who were not clearly mentally retarded (attending special schools) or autistic/autistic-like (who sometimes attend special autism units) in western Göteborg with a view to finding all cases of autism/Asperger syndrome in those schools (Holmström, 1985). At the time of the screening a total of about 10,500 children in the 7-16-yr age range attended these schools. The teacher interviewed the school nurse, the school psychologist and the head of each school in accordance with a structured questionnaire containing 22 questions relating to (1) social impairment, (2) language peculiarities, (3) oddities of personality, (4) autism type behaviours, and (5) achievement problems. The nurse, the psychologist and the headmaster were asked "do you know of any child in this school who shows any of these symptoms?" The questionnaire was then completed in detail for children who had such symptoms. Altogether 10 cases (eight boys, two girls) with problems in all of the first four of the five categories just referred to were found. Only five of these 10 children (out of a total of 22 who were reported to have severe problems in at least two areas) have been seen by one of us (C. G.). Four (all boys) were diagnosed as suffering from Asperger syndrome. The fifth case (also a boy) conformed to the clinical picture of classical Kanner autism with autistic type aloofness, withdrawal, no communicative speech, echolalia, no particular interests, resistance to change and stereotypies. One girl was excluded from the group of possible cases after the remedial education teacher had seen her and reported in detail about her to C. G., who decided that she could not fulfil criteria for Asperger syndrome or autism. For various reasons it has not been possible to contact the other four children and their parents. School nurses and child psychiatrists have maintained that these families would object to being enrolled in a research project and have refused even to ask them if they would consider allowing the child to be clinically examined by one of us. Providing that the remaining four cases also receive a diagnosis of Asperger syndrome, we would be left with a maximum population frequency in the 7-16-yr age range of 8 per 10,000.

This study has several limitations—e.g. that the child's teacher was not personally interviewed and that no psychiatric diagnostic work-up was originally planned. Also, the screening device has not been specifically tested for reliability or validity. Nevertheless, with all its drawbacks, we think it does provide us with a clue as to the scope of the problem. Furthermore, the number of typical Asperger syndrome cases in the specialized autism classrooms is small. According to the present authors, who know these children personally, no more than one child (a girl) in the age-specific

area population would be diagnosed in the Asperger category. We are also in contact with one boy and one girl in the age-specific area population who attend normal schools but who were not identified by the screening procedure. All three cases were of normal or near-normal full scale IQ. These three cases of Asperger syndrome would increase the prevalence from 8 to 11 per 10,000.

## Epidemiological study of autism spectrum disorders in London

Lorna Wing and her group, (e.g. Wing and Gould, 1979; Wing, 1981b) carried out a study in Camberwell, London in the 1970s in which all mentally and physically handicapped children under age 15 yrs were screened in order to identify cases of early childhood autistic and autistic type disorders, and severe mental retardation. Wing found 0.6 per 10,000 who had the combination of Asperger syndrome and mild mental retardation and a further 1.1 per 10,000 who had been "autistic" in early life but who later in life better fitted the Asperger stereotype.

#### Other epidemiological studies

Apart from the studies mentioned, there are no other population-based estimates of the frequency of Asperger syndrome. However, it is of some interest that Wolff and Chick (1980) in Scotland found that 3-4% of a child psychiatric clientele were "schizoid". Some of these patients resembled the groups we have here referred to as Asperger syndrome.

#### Conclusions

We have not been able to find any good population-based study of the prevalence of Asperger syndrome. However, the studies reviewed all suggest that the frequency is considerably higher than for autism defined according to Rutter (1978) or DSM-III-R (APA, 1987) criteria (Table 1). Most studies indicate a relatively stable low rate of infantile autism in the range of 2.0–4.5 per 10,000 (Lotter, 1966; Brask, 1970; Wing & Gould, 1979; Gillberg, 1980; Bohman, Bohman, Björck & Sjöholm, 1983; Steffenburg & Gillberg, 1986). Very recently, somewhat higher frequencies have tended to be reported (see Steffenburg & Gillberg, 1986 and Bryson et al., 1988). The increase—at least in the Swedish studies—does not seem to affect the "classical Kanner group", that is those who have both autism and mild-moderate mental retardation, and so appears to be the result of better screening and coverage among the severely mentally retarded and those with higher levels of intelligence.

Our pooled findings on the basis of the small literature which exists in the field of Asperger syndrome leave us with frequency figures in the 10-26 per 10,000 range (counting only those who are not mentally retarded). It appears that only a small fraction of the total number of Asperger syndrome cases are to be found among those with mild mental retardation. In Lorna Wing's (1981b) series of referral and screening cases, 20% were not of "normal or high intelligence". It is not clear whether Wing

Table 1. Asperger syndrome epidemiology

Study and population screened	Asperger syndrome prevalence (No. of cases per 10,000)		
	Without mental retardation	With mental retardation	
Gillberg et al. (1982) 6-7-yr-olds from general population; intense study of clumsy children with attention problems and "no-problem" children	26/10,000		
Gillberg et al. (1986) 13-17-yr-olds from general population: intense study of all children with IQ < 70		0.4/10,000	
Holmström (1985) 7–16-yr-olds screened in normal schools; no clinical ascertainment	10-11/10,000		
Wing & Gould (1979) 0-15-yr-olds from handicapped population		0.6-1.7/10,000	

considered these 20% to be mentally retarded or not. Gillberg (1988) in a recent paper found 17% of a clinic sample to be mildly mentally retarded. Taken together, the data would seem to imply that in the general population Asperger syndrome is only very rarely connected with mental retardation, but that in a clinic population the association is fairly common, possibly because of the increased risk of psychiatric morbidity in a child with two handicaps rather than only one.

Of the epidemiological data presented in this review paper, only the population frequencies of Asperger syndrome in the mentally retarded can be clearly said to be relatively firmly based. Wing & Gould (1979) screened all the mentally handicapped (albeit only the severely handicapped) children in one area. Gillberg et al. (1986) actually saw and clinically examined every single child in the 13–17-yr age range who had a diagnosis of mental retardation. From these studies it seems obvious that no more than 1–2% of all mildly mentally retarded children show concomitant Asperger syndrome and that among the severely mentally retarded it is not seen at all. In this low IQ group, of course, it merges with autism and other autistic-like conditions and becomes inseparable as a diagnostic entity. Even though psychiatric diagnostic error could have occurred in a small number of cases in the series of mentally retarded children examined by Gillberg and co-workers, the relative contribution of mentally retarded children with Asperger syndrome to the whole population of such children would not be greatly altered.

In the range of normal intellectual functioning, we can only say that the prevalence

of Asperger syndrome is still unknown but that it is more common than infantile autism and that it is likely to be at least in the 10-26 per 10,000 range.

Clearly, conclusions at this stage can only be tentative, particularly since most of them rest on the shaky basis of 11 definite cases of Asperger syndrome.

We are, of course, aware of the discussion about whether or not Asperger syndrome and infantile autism are on a continuum with each other. However, in this paper we refrain from entering into that discussion and refer the reader elsewhere (Wing, 1981a; Schopler, 1985; Bowman, 1988). From the clinical point of view it seems to us that a continuum of disorders with Lorna Wing's "triad" patients with severe mental retardation at one end (Wing, 1981b), followed by Leo Kanner's autism cases with mild-moderate mental retardation, and then Asperger syndrome children on the middle portion and Gillberg's children with deficits in attention, motor control and perception (DAMP) at the other extreme is a valid hypothetical construct which deserves further critical examination (Fig. 1).

Triad	Kanner	Asperger	DAMP
extreme handicap			mild handicap

Fig. 1. Autism spectrum disorders.

#### References

American Psychiatric Association (1987). DSM-III-R. Diagnostic and statistical manual of mental disorders (3rd edn-revised). Washington DC: APA.

Asperger, H. (1944). Die "Autistischen Psychopathen" im Kindesalter. Archiv für Psychiatrie und Nervenkrankheiten, 117, 76-136.

Bohman, M., Bohman, I. L., Björck, P. O. & Sjöholm, E. (1983). Childhood psychosis in a northern Swedish county: some preliminary findings from an epidemiological survey. In M. H. Schmidt & H. Remschmidt (Eds), *Epidemiological approaches in child psychiatry* (Vol. 2) (pp. 164-173). Stüttgart: Thieme-Stratton Verlag.

Bowman, E. P. (1988). Asperger's Syndrome and autism: the case for a connection. *British Journal of Psychiatry*, 152, 377-382.

Brask, B. H. (1970). A prevalence investigation of childhood psychosis. Paper given at the 16th Scandinavian Congress of Psychiatry.

Bryson, S. E., Clark, B. S. & Smith, I. M. (1988). First report of a Canadian epidemiological study of autistic syndromes. *Journal of Child Psychology and Psychiatry*, 29, 433-445.

Gillberg, C. (1980). Maternal age and infantile autism. Journal of Autism and Developmental Disorders, 2, 153-158.

Gillberg, C. (1983). Perceptual, motor and attentional deficits in Swedish primary school children. Some child psychiatric aspects. *Journal of Child Psychology and Psychiatry*, 24, 377-403.

Gillberg, C. (1984). Infantile autism and other childhood psychoses in a Swedish urban region. Epidemiological aspects. *Journal of Child Psychology and Psychiatry*, 25, 35-43.

Gillberg, C. (1985). Asperger's syndrome and recurrent psychosis—a neuropsychiatric case study. *Journal of Autism and Developmental Disorders*, 15, 389-398.

Gillberg, C. (1988). Asperger syndrome in 23 Swedish children: a clinical study. Developmental Medicine and Child Neurology, (in press).

- Gillberg, C., Rasmussen, P., Carlström, G., Svenson, B. & Waldenström, E. (1982). Perceptual, motor and attentional deficits in six-year-old children. Epidemiological aspects. *Journal of Child Psychology and Psychiatry*, 23, 131-144.
- Gillberg, C., Persson, E., Grufman, M. & Temnér, U. (1986). Psychiatric disorders in mildly and severely mentally retarded urban children and adolescents. *British Journal of Psychiatry*, 149, 68-74.
- Gillberg, I. C. (1987). Deficits in attention, motor control and perception. Follow-up from pre-school to the early teens. Thesis, Uppsala University.
- Gillberg, I. C. & Gillberg, C. (1987). Follow-up of 117 school children with so-called MBD. Paper given at the First Nordic Symposium on MBD, Sandefjord, Norge (1987).
- Hagberg, B., Hagberg, G., Lewerth, A. & Lindberg, U. (1981). Mild mental retardation in Swedish school children. I. Prevalence. *Acta Paediatrica Scandinavica*, 70, 441-444.
- Holmström, B. (1985). Barn med kontakthandikapp i grundskolan. (Children with social deficit handicap conditions in normal schools). University of Göteborg (in Swedish).
- Kanner, L. (1943). Autistic disturbances of affective contact. Nervous Child, 2, 217-250.
- Lotter, V. (1966). Epidemiology of autistic conditions in young children. I. Prevalence. Social Psychiatry, 1, 124-137.
- Rutter, M. (1978). Diagnosis and definition. In M. Rutter & E. Schopler (Eds), Autism: A reappraisal of concepts and treatment (pp. 1-25). New York: Plenum.
- Schopler, E. (1985). Editorial: convergence of learning disability, higher-level autism, and Asperger's syndrome. *Journal of Autism and Developmental Disorders*, 15, 359-360.
- Steffenburg, S. & Gillberg, C. (1986). Autism and autistic-like conditions in Swedish rural and urban areas: a population study. *British Journal of Psychiatry*, 149, 81-87.
- van Krevelen, D. A. (1971). Early infantile autism and autistic psychopathy. *Journal of Autism and Childhood Schizophrenia*, 1, 82-86.
- Wing, L. (1981a). Asperger's syndrome: a clinical account. Psychological Medicine, 11, 115-129.
- Wing, L. (1981b). Language, social and cognitive impairments in autism and severe mental retardation. Journal of Austism and Developmental Disorders, 11, 31-44.
- Wing, L. & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Austism and Developmental Disorders*, 9, 11-29.
- Wolff, S. & Chick, J. (1980). Schizoid personality in childhood: a controlled follow-up study. *Psychological Medicine*, **10**, 85–100.

This document is a scanned copy of a printed document. No warranty is given about the accuracy of the copy. Users should refer to the original published version of the material.