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## The outcome in children with childhood autism and Asperger syndrome originally diagnosed as psychotic. A 30-year follow-up study of subjects hospitalized as children

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**Abstract** This follow-up study reports data on 18 children fulfilling the ICD-10 criteria for childhood autism (n=9) and Asperger syndrome (n=9). In connection with the present study the original child psychiatric records were reassessed according to the ICD-10 criteria. The children were followed over a period of 30 years. The mean age at the time of study was 38 years. The results show that in adulthood the autistic patients had a poorer out-

come than children with Asperger syndrome as regards education, employment, autonomy, marriage, reproduction and the need for continuing medical and institutional care. Particular attention is given to pharmacotherapy and the relationship between the childhood disorder and psychiatric morbidity in adult life.

**Key words** Asperger syndrome – childhood autism – longitudinal study – outcome

### Introduction

During recent years, a number of follow-up studies have been published on autistic children. These have been based on clinical samples (7, 22) and on population investigations (9, 21, 30). However, only few articles concern the course in adult life (12, 13, 14, 15, 24, 27, 28). The strongest predictors of long-term outcome with respect to overall social functioning, as well as academic attainment are the child's cognitive level and degree of language impairment (4, 18, 19, 21). Recent studies have provided a very optimistic picture of the academic abilities and independent functioning in high-functioning autistic adolescents and adults than was reported 20 years ago (20, 28). As far as the present authors are aware, no articles have been published which describe the course in adult life of children with Asperger syndrome.

In Denmark, a cohort of child psychiatric in-patients have been followed-up for 30 years. The result from a 20-year follow-up (2, 3) and a 30-year follow-up (16, 17) have been published previously. The aim of the present investigation was to describe the 30-year course

and outcome for childhood autism (CA) and Asperger syndrome (AS).

### Subjects and methods

The sample consisted of 322 children (189 boys and 133 girls) who were admitted at the department of child psychiatry, Bispebjerg Hospital and Rigshospital from the middle of 1949 until the middle of 1951. These were the only child psychiatric departments in Denmark at that time.

The size and makeup of the sample were originally chosen in 1970 in connection with a 20-year follow-up study which, among other things, investigated the risk of developing manic-depressive psychoses in a child psychiatric clientele (2). The necessary number of boys to test the hypothesis was attained before the proportionate number of girls. In other words, in a total sample of 412 patients consecutively admitted 90 boys have been omitted. The sex distribution therefore does not correspond to the normal one in a child psychiatric

sample. Particular attention was paid to a so-called psychotic group. The case records of children with a diagnosis of psychosis or borderline psychosis during 1949–1951 or later (upto 1970) were examined by two experienced child psychiatrists and blindly reassessed according to ICD-8 (3). After this revision, 23 patients were considered to be either psychotic ( $n=17$ ) or borderline cases ( $n=6$ ) from 1949 to 1951. The psychotic group could be differentiated in 10 children with proto-infantile psychoses, 3 with nonspecific psychoses and 4 with previous infantile psychoses. These 23 patients constituted our sample.

Five of the 23 patients were excluded. The first was a boy aged 10 years who fulfilled the criteria for an ICD-10 diagnosis of emotionally unstable personality disorder. The second was a 13 year-old girl who presented a definitely schizophrenic condition. The third patient was a girl aged 13 years with familial deaf-mutism in whom an ICD-10 diagnosis of another psychoses was established. The fourth patient was a boy aged 10 years and the fifth a boy aged 11 years who had encephalitis with transient pareses at the age of 8 years. Both these patients were diagnosed as having schizotypal disorders.

Interrater reliability was studied in the following way: The original 23 child psychiatric records were read independently by the two authors in 1992, and independent ICD-10 diagnoses were established on the basis of the information available in these records. In cases of doubt the diagnosis assigned by the first author was used. Agreement was reached in all cases but one (95%) for a diagnosis of Pervasive Developmental Disorders. However, agreement was less perfect for the subgroups CA and AS, 67% and 73%. The diagnostic revision left us with 9 children fulfilling the ICD-10 criteria for CA and AS respectively. In 1 single patient there was some doubt about the age at onset of the disease. Nevertheless, this patient was included because all the other criteria for a diagnosis of CA were present. Fourteen of the 18 patients had been admitted to psychiatric departments as adults. In 1996 these patients' case notes were reassessed according to ICD-10 (36) by the first author.

The study was planned as a register study. By means of linking the personal identification number with different registers, the status of each of these persons as of December 31, 1980 could be determined regarding domicile, mortality, causes of death, criminal offences, disability pension, marital status, vocational training and socio-economic status. The Institute of Psychiatric Demography provided information about patients admitted to adult psychiatric departments. In addition, medical case records of patients admitted to adult psychiatric departments from 1950 to 1980 were examined. As a result of the unique Danish personal identification number, follow-up with no dropouts proved possible.

Detailed accounts of the makeup and selection of the primary group of patients and the psychiatric morbidity at follow-up in 1980 have been published earlier (16, 17).

## Results

Some important background factors and outcome in individual cases are described in Table 1. The sex ratio is not typical for a child psychiatric population but due to selection of the sample as described above. The average age for admission at a department of child psychiatry was 9.2 years for the AS group compared with 5.9 years for the CA group. All the children in the AS group except for 3 were of normal intelligence. Definitions are presented in the Appendix. The 3 exceptions had an IQ in the near average range. In the CA group, 2 of 9 children had normal intelligence. The patients were tested with either the Bühler-Hetzer or Binet-Simon Scale.

Eight of 9 patients in the AS group (87%) could attend ordinary school system while 1 was taught at home. None of the children in the CA group could attend the ordinary school system.

During late puberty, 3 patients in the CA group (33%) and 2 in the AS group (22%) underwent marked persistent deterioration as a rule in the form of hyperactivity, aggression and destructiveness accompanied by loss of some or all the linguistic abilities and slow intellectual dementia. A known medical condition was observed in a single patient who had a concomitant occurrence of AS and myxoedema diagnosed at the age of 3 months. During the follow-up period 2 patients in the CA group (22%) and 1 in the AS group (11%) developed epileptic seizures. At the time of follow-up the average age in the AS group was 39.1 years as compared with 36.5 years in the CA group.

## Mortality

Two patients had died. Patient No. 9 died at the age of 35 years from internal haemorrhage after a traffic accident. Patient No. 11 who was a chronic psychiatric patient in an institution died at the age of 33 years as a result of volvulus which was recognised too late.

## Vocational training and occupational status

Two patients in each group had received training. In the AS group, patient No. 1 was trained as a gardener but has hitherto been employed as an insulator. Patient No. 5 worked for many years as a driver, and then in

the fish industry until he received a disability pension at the age of 33 years. Before this, he was divorced after a seven year long marriage and he was unable to live with his two children. Four further patients in the AS group were registered with the labour market prior to 1980 and have carried out fully-paid unskilled work. Patient No. 2 was employed as an unskilled worker but at the age of 31 years he was awarded disability pension. Patient No. 4 who lives with his mother was awarded disability pension at the age of 22 years but has performed paid work as e.g. gatekeeper, elevator attendant and office boy. During the year before withdrawal he worked as a temporary office boy in a oil firm and thereafter received unemployment benefits. He applied for a pension as he realised that he was slow and had difficulty in remembering things and was distractable. He was awarded full disability pension from the age of 38 years. Patient No. 6, who also lives with his parents has had sheltered employment in a cardboard box factory – a job which his parents arranged. This factory closed when he was 36 years and from that time he was awarded disability pension. Patient No. 8 obtained sheltered work in a cardboard factory with his parents' help. When his mother died, he was admitted at a psychiatric hospital and no longer worked.

In the CA group patient No. 12 employed her outstanding talent for drawing to be trained as a china painter. She has received disability help since the age of 21 but has had her main income as a china painter and has been with the same industry for more than 25 years. She was able to retain her job thanks to considerable tolerance from her fellow-employees and her employer. Patient No. 15 received social help until the age of 36 years. After a long period of rehabilitation, and having been rejected by the first training institution because of odd behaviour, she was trained as a nursery school teacher at the age of 36 years and has since had several brief periods of employment as a substitute.

### Disability pension

Details about disability pension are provided in Table 1. In Denmark a disability pension is only given to a person above the age of 16 years on the basis of a lasting reduction in vocational capacity. Seven patients (78%) in both the AS and the CA groups received disability pensions.

### Marital status and children

Two patients in the AS group were married (22%). Patient No. 1 has been married for 19 years and has four children. Patient No. 3 has been married for 20 years

and has two children. Two patients have been divorced after marriages for 15 and 7 years, respectively. None of the patients in the CA group have been married or have children.

### Residence

Five patients in the AS group (56%) had their own homes and were independent or managed with minimal supervision. Two patients lived with their parents. In the CA group, 3 patients (33%) had their own homes while 1 still lived with his parents. The majority (56%) lived in psychiatric institutions or institutions for mentally retarded.

### Criminality

Only 1 patient had a criminal record during the 30 years. Patient No. 1 was sentenced to a fine at the age of 24 years because of theft.

### Psychiatric morbidity

The age at first admission to an adult psychiatric department and an ICD-10 diagnosis in adult life are shown in Table 2. There was a difference in the incidence of psychiatric illness between the two groups (Table 2). Three patients in the AS group as compared with 5 patients in the CA group were chronic patients. The daily need for care was, however, much greater for patients in the CA group (Table 1). The age at first admission at a department for adult psychiatry was identical in the two groups, 17 years.

In the AS group, 3 patients had not been admitted to a psychiatric department and had not received neuroleptics during the 30-year period. In the remaining 6 patients (67%), only superimposed psychiatric illness was present in two cases (patient No. 5 and patient No. 8). Patient No. 5 had a mental breakdown at the age of 19 years shortly after being called-up for military service. At the age of 28 years, he was admitted with depressive symptoms in connection with divorce. Since then, he has attended outpatient psychiatric treatment. His symptoms consisted of narcissism, contact difficulties, a defective grasp of reality that took the form of day dreaming during well-compensated phases but could develop into paranoid ideation, anxiety manifested as psychosomatic symptoms, aggressive impulses and fantasies of molesting unknown women, and recurrent compulsions.

Patient No. 8 was admitted at the age of 15 years with an acute psychosis in a condition which resembled catatonic stupor. He responded well to treatment with

**Table 1** Background Factors and Outcome

No.	Sex	Diagnosis	IQ <sup>1</sup>	Age in years	Vocational education	Occupation <sup>2</sup>
1	M	AS	A	43	Gardener	Insulator
2	M	AS	A	44		DP **
3	F	AS	A	42		DP
4	M	AS	A	39		DP **
5	M	AS	NA	36	Driver	DP **
6	M	AS	NA	33		Sheltered workshop
7	F	AS	NA	39		DP
8	M	AS	A	37		Sheltered workshop
9	M	AS	A	Dead		Dead
10	M	CA	NA	33		Sheltered workshop
11	M	CA	MMR	Dead		Dead
12	F	CA	NA	37	Porcelain painter	Porcelain painter
13	M	CA	MMR	39		Attends day program at PH
14	F	CA	A	38		Attends day program at PH
15	F	CA	A	37	Educationist	Kindergarten teacher
16	F	CA	SMR	38		Occupational therapy in PH
17	F	CA	NA	32		Occupational therapy in PH
18	F	CA	MMR	38		Occupational therapy in MR

  

No.	Age at disability pension	Marital status	Children	Residence	Required supervision	Outcome <sup>3</sup>
1	Not granted	Married	4	With spouse	Nil	Good
2	20	Divorced	0	Apartment	Nil	Fair
3	18	Married	2	With spouse	Minimal	Good
4	22	Not married	0	With parent	Minimal	Good
5	33	Divorced	2	Apartment	Nil	Fair
6	Not granted	Not married	0	With parents	Minimal	Fair
7	34	Not married <sup>5</sup>	0	Apartment	Minimal	Fair
8	16	Not married	0	Psychiatric institution <sup>6</sup>	Moderate	Poor
9	17	Not married	0	Foster home	Moderate	Poor
10	19	Not married	0	Institution for MR <sup>6</sup>	Moderate	Poor
11	18	Not married	0	Psychiatric institution	Constant	Very poor
12	21 <sup>4</sup>	Not married	0	Apartment	Nil	Fair
13	26	Not married	0	Apartment	Nil	Good
14	16	Not married	0	With parents	Constant	Very poor
15	Not granted	Not married <sup>5</sup>	0	Apartment	Nil	Good
16	22	Not married	0	Psychiatric institution	Constant	Very poor
17	22	Not married	0	Psychiatric institution	Constant	Very poor
18	22	Not married	0	Institution for MR	Constant	Very poor

<sup>1</sup> SMR (IQ<50), MMR (IQ 51–70), NA (IQ 71–85), A (IQ>85). <sup>2</sup> DP = Disability pensioner; PH = Psychiatric hospital; MR = Institution for mentally retarded;

\*\* Previous full-time unskilled work. <sup>3</sup> Outcome (See appendix for definitions). <sup>4</sup> Disablement benefit; <sup>5</sup> Cohabitation; <sup>6</sup> Lived with parents until their death

Largactil and could be discharged in his habit condition after three weeks. He was readmitted at the age of 18 years with the aim of finding an occupational place. He appeared peculiar, his speech was slow and drawling, suggesting an accent or a dialect. When Largactil was withdrawn, his behaviour which suggested hallucinations was aggravated. On one occasion, he admitted

that he had probably heard voices coming from inside for a period of 3–4 years. These were not only friendly but also scolding voices from persons in his family and friends. At the age of 37 years he was placed in a psychiatric nursing home. During a conversation with the psychiatrist, he denied that he had ever been hallucinating, and felt the doctors had misunderstood him. He did

**Table 2** The relationship between child psychiatric diagnosis and adult psychiatric morbidity

No.	Sex	Diagnosis	Age in years at first admission adult psychiatric department	ICD-10 at follow-up
1	M	AS	15	Schizoid personality disorder
2	M	AS	15	Asperger syndrome
3	F	AS	Not admitted	Not stated
4	M	AS	Not admitted	Not stated
5	M	AS	19	Asperger syndrome
6	M	AS	Not admitted	Not stated
7	F	AS	19 <sup>1</sup>	Asperger syndrome
8	M	AS	15 <sup>1</sup>	Schizotypal disorder
9	M	AS	19 <sup>1</sup>	Schizotypal disorder
10	M	CA	Not admitted	Childhood autism
11	M	CA	12 <sup>1</sup>	Childhood autism
12	F	CA	21	Childhood autism
13	M	CA	15	Asperger syndrome
14	F	CA	18 <sup>1</sup>	Childhood autism
15	F	CA	23	Asperger syndrome
16	F	CA	13 <sup>1</sup>	Childhood autism
17	F	CA	16 <sup>1</sup>	Undifferentiated schizophrenia
18	F	CA	15 <sup>1</sup>	Childhood autism

<sup>1</sup> Chronic patient (see text for details)

speak with other persons in his fantasy but did not consider that hallucinating.

The remaining 4 patients were admitted either for investigation due to occupational or housing placements or symptomatology which had been recognised during admission to child psychiatry departments. Two of the patients in the AS group were diagnosed in adult life with schizoid personality disorder and schizotypal disorder. The first diagnosis was established when the patient was admitted at a psychiatric department at the age of 15 and is thus associated with considerable uncertainty. The other diagnosis was based on comprehensive observations and descriptions in adult life.

In the CA group, massive psychiatric illness was present in 8 out of 9 patients (87%). Patient No. 10 had never been admitted. At the age of 22, he was registered under the service for the care of the mentally retarded and lived with his mother until she died. From the age of 32, he lived in a sheltered housing arrangement for mentally retarded individuals. Detailed descriptions of behaviour were available, and this patient is still considered to fulfil the criteria for a diagnosis of CA. He had been treated with neuroleptics since the age of 25 years.

At the age of 25 years Patient No. 14 suffered from delusions, hallucinations and catatonic phenomena. 34 years old she was throwing porcelain, claiming that the voices told her to do so. Patient No. 15 was admitted on two occasions at the ages of 23 and 25 in connection with problems at work and feelings of insufficiency. She is the only patient in this sample who has been treated with antidepressants with good effect. Since then, she has not experienced depressive epi-

sodes. Whether there was an endogenous depression or not remains uncertain. Patient No. 17 was examined by a psychiatrist 16 years old. She had a good communicative speech, had a normal intelligence according to a WAIS test, and a good social prognosis was stated. Twenty-one years old she was found autistic with no emotional response, she was restless and hallucinated. Thirty years old she was offered a room in the nursery students' building, but she refused, stating that she could not be alone when the voices started to mock her. Thirty-one years old while writing letters she stated that the voices forbid her to write to her father who, by the way, usually sends her parcels. She complains that the mind of another patient influenced her. She experienced the voices as small moons having been placed in her brain and with a shutter to creep through. One year later she stated that the voices were saying awful things to her, partly with a sexual content. Thirty-four years old she talked about ghosts continuously appearing. She was supposed to be visual hallucinating. Altogether she definitely fulfilled the ICD-10 criteria for schizophrenia.

Two patients in the CA group have now been diagnosed as having AS. The reason for this is simply that, in adult life, they fulfil the criteria for AS but only some of the criteria for CA. It would have been more satisfactory to employ the DSM-III diagnosis of infantile autism, residual state. Five patients have had chronic courses of repeated admissions or continuous stays in psychiatric institutions from adolescence or early adult life. A chronic course is defined as either continuous stay in hospital, more than 20 admissions during the follow-up period or residence in a sheltered dwelling and need for daily support from others.

**Table 3** Pharmacotherapy during follow-up period

First prescription				Prescription at follow-up	
No.	Diagnosis	Age (years)	Drug	Drug	Daily dose in mg
1	AS	Never		None	
2	AS	44		Phenobarbital/ergotamine	Unknown
3	AS	Never		None	
4	AS	Never		None	
5 <sup>1</sup>	AS	28	Chlorprothixene	Chlorprothixene	75
6	AS	Never		None	
7 <sup>1</sup>	AS	20	Chlorpromazine	Trifluoperazine	20
8 <sup>1</sup>	AS	15	Chlorpromazine	Perphenazine	8 <sup>2</sup>
				Pimozid	6
9	AS	15	Chlorpromazine	Dead	
10 <sup>1</sup>	CA	25	Chlorpromazine	Levomepromazine	75
				Chlorpromazine	75
11 <sup>1</sup>	CA	12	Chlorpromazine	Dead	
12	CA	13	Chlorpromazine	Chlorprothixene	200 <sup>2</sup>
13	CA	24	Perphenazine	None	
14	CA	18	Reserpine	Clopendithiol	100 <sup>2</sup>
15	CA	27	Perphenazine	None	
16 <sup>1</sup>	CA	13	Chlorpromazine	Perphenazine	48 <sup>2</sup>
17	CA	15	Clopendithiol	Penfluridol	40 o.a.w. <sup>3</sup>
				Clopendithiol	125 <sup>2</sup>
18 <sup>1</sup>	CA	15	Chlorpromazine	Haloperidol	30 <sup>2</sup>

<sup>1</sup> Continuous treatment with neuroleptics since first prescription

<sup>2</sup> Antipsychotic dose level

<sup>3</sup> o. a. w. = Once a week

## Pharmacotherapy

All case records were scrutinized for information on possible medication including dosage and duration of the treatment. The treatment was rated if administered for a period of at least six months during the follow-up period. During the 30-year period, neuroleptics had been administered to 5 patients in the AS group (Table 3). Four patients never received neuroleptics or sedatives. All the patients in the CA group received neuroleptics. The age at first prescription was 19.5 years (15–28 years) in the AS group and 18.0 years (12–27 years) in the CA group. Three patients in the AS group and 4 patients in the CA group, respectively, were in continuous neuroleptic treatment since the first prescription. The patients in the AS group tended to be slightly older than in the CA group (average age 23.8 years compared with 18.9 years). On follow-up in 1980, 2 patients in the CA group had been without medication for 9 and 12 years, respectively, 1 patient in the AS group and 5 patients in the CA group received doses corresponding to an antipsychotic level in 1980. Most patients in the CA group had received a variety of different types of neuroleptics during 30 years, suggesting that the symptoms which prompted the use of medication: anxiety, motor restlessness, aggression and self-destructive behaviour, had in fact been very difficult to control. These symptoms were the reason for pharmacotherapy treatment.

## Overall outcome

The overall outcome is shown in Table 2 (see appendix for definitions). None of the patients in the AS group had a very poor outcome and only 1 had a poor outcome (13%). In the CA group, 5 patients had poor or very poor outcomes (63%). In both groups normal intelligence predicted a good outcome.

## Discussion

The limitations of the study need to be addressed. Firstly, the sample is based on clinical experiences which originates from a time when the two child psychiatric departments were the only such departments in Denmark and the concept of child psychosis was only slowly becoming accepted in Danish child psychiatry. It is obvious from the following calculation that we are dealing with a highly selected sample: A total of 1164323 children were born in Denmark from 1934 to 1948. Assuming the prevalence of CA being 4.5 per 10000 (26) and 36 per 10000 for AS (5) we could expect that approximately 522 children with CA and approximately 4176 with AS were born during the period. The 18 children in this investigation thus constitute less than 2% of the potential number of children with CA and just over 0.2% of the potential number of children with AS in Denmark. While it is unlikely that any of

the other 299 in-patients had CA, an examination of all the case records might have revealed some cases of AS, masked by co-morbidity among this bigger group. Why these children in particular were admitted remains unexplained. One explanation may be that many of the children were hospitalized before admission at a department for child psychiatry. During admissions such as these, 3 children were examined by child psychiatrists and admission to a department for child psychiatry was suggested.

Three further children were transferred directly to departments for child psychiatry and 1 child was admitted at the age of 3 years shortly after the first seizure. Five of these 7 children belonged to the CA group. Secondly, revision of diagnoses based on case notes always raises problems of reliability. In addition, the use of ICD-10 was new to both of the investigators. There was good agreement between the two investigators regarding a diagnosis of Pervasive Developmental Disorders but there were considerable problems with both the diagnoses of Asperger syndrome and childhood autism.

In some cases there was disagreement whether a patient should be diagnosed as having Asperger syndrome or childhood autism, a dilemma which has also been emphasized by others (6, 31). Whereas the reliability figures for ratings of CA and AS from the child case records did not reveal any great differences, the greatest problems were encountered in the AS group. The reason for this may be that the more obvious signs of CA were probably recorded in the case notes. The diagnosis of AS was not accepted in 1950. In several of the case records, the similarity to patients described by Asperger with autistic psychopathy was admittedly mentioned. The uncertainty may also be due to the investigators having arrived at different opinions on how to interpret the data from the case notes. Problems in reliability would have been reduced if we had had the opportunity of employing a diagnostic interview or standardised instruments to establish the presence or absence of autistic symptomatology.

Finally, when we compare our results with other follow-up studies, it must be noted that an unrepresentative sample is involved; all being in-patients and the sex ratio and the intellectual level of function is atypical. On the other hand the sample must be regarded as unique, partly because this group of patients has been followed-up by means of continued follow-up investigations and also because all of the patients now are in the middle of their adult lives. However, whether or not our sample was selected, the results for a poor or very poor outcome (63%) were in good agreement with the results from population investigations in Göteborg (9) and Middlessex (21) of 59% and 62%, respectively, and with the proportions of 61–74% reported in Lotter's review (22).

The optimistic expectations which recent follow-up investigations of high functioning autistic children sug-

gest (20, 27, 28) may be partly based on a more purposeful training of autistic children and adolescents. Much progress has been made in the education of children with autistic spectrum disorders since our subjects left school, a progress from which they could therefore not benefit.

Autism is particularly likely to be associated with specific medical conditions (8). With the exception of 1 patient, none of our patients had accompanying medical conditions. One patient with AS was diagnosed as having myxoedema at the age of 3 months. This was perhaps a coincidence but recently a possible link between hypothyroidism in early foetal/childhood development and autism/autism spectrum disorders had been suggested (10).

Definite improvement in the condition occurred in only 1 patient, a male with childhood autism who began gradually to become more open towards his nearest family from the age of 20 years and with no socially unsuitable remarks. He studied literature on psychology, psychiatry and astronomy and occasionally had detailed discussions with the medical staff of the psychiatric hospital where he had been placed. He revealed an intimate knowledge of Kanner's conception of autism and was convinced that he had had childhood autism as a child. He was also able to account for the basis for his stereotypical behaviour and peculiar interests that he had, and could describe how he had felt it necessary to isolate himself from others. He chose to remain in hospital for a long time until he became established in his own flat but he still retains a close relationship with a psychiatric day centre.

#### Social issues

Where the social outcome was concerned, none of the patients in the CA group were married. Two women had, however, lived for several years with a boy-friend. In contrast to this, 4 patients in the AS group were or had been married. Three had children. The marriage rate appears to be proportionately high but due to the limited number of relevant studies on this subject we are unable to state whether this is a new finding.

Three patients in the entire sample still lived with their parents and 2 others had lived with their parents until they died, after which both were placed in institutions. This prolonged parental care of socially severely handicapped children had also been reported in other investigations (9, 24, 27). This observation appears to be a recognition of the fact that there are very few suitable collective residences for these patients.

Only 4 of the 18 patients had any occupational training. None of the patients had a university degree. Nevertheless, the great majority of the patients in the AS group had a salaried employment and had been re-

gistered with the labour market mainly on normal terms. One third of the patients had considerable help, from their parents in particular, to obtain employment and as adults they still lived with their parents. At follow-up, only 1 patient had a job. Social events such as loss of supportive parents, divorce, closing of factories etc. appear to be factors which limited the possibilities of permanent employment for these patients. Circumstances were quite different where the CA group was concerned. The great majority had never been registered with the labour market. This social outcome is in good agreement with other investigations although these have not followed the patients up until middle adult life. With one single exception (27), none of the long-term follow-up investigations have reported patients who had married and none have mentioned CA patients with children. In our sample, only 1 patient in the AS group had committed a crime at the age of 24 years for which he was fined. This particular patient had had a good outcome. We have thus not been able to confirm the findings published in recent years that a little group of individuals with autism and Asperger syndrome may be involved in crime or violent behaviour (1, 7, 25, 32).

#### Pharmacotherapy

None of the patients received medication as children. During early puberty, 33% of the CA group received neuroleptics which were prescribed in connection with deterioration or disintegration. The majority of the patients in the CA group received continuous treatment with neuroleptics from early adult life and, in all cases, the dosage was of an antipsychotic level. This finding was considerably higher than in the investigation by Gillberg and Steffenburg (9) where 1/3 of the CA patients were treated with neuroleptics on follow-up. Gillberg's patients were, however, in the age group of 16–23 years at follow-up. Other studies have reported even lower frequencies of neuroleptic treatment (13, 27). In a 20-year follow-up study of 20 patients with childhood schizophrenia, 12 patients (60%) were living in institutions for the mentally retarded or in psychiatric hospitals at the time of follow-up and all of them were receiving some form of medication. The remaining 8 (40%) were living at home and only 2 were on medication. The drugs employed were mainly major tranquilizers and/or anticonvulsants (12).

On the basis of the symptomatology exhibited by the patients, it is understandable that treatment with neuroleptics was employed. Two tendencies were apparent: Where a small group of patients was concerned it proved possible to employ one or very few neuroleptics which could be adjusted according to the condition of the patient and where a definite therapeutic effect was obvious. Where the other group of patients was con-

cerned, it was characteristic that many different drugs were tried, e.g., Lithium, ECT, and 1 patient was even subjected to lobotomy in an attempt to stop the severe anxiety and self-destructive behaviour. Nevertheless, the psychiatrists had to admit that treatment did not alter the symptoms presented by these patients to any great extent and that these symptoms had a tendency to come in a certain periodicity. No evidence could be found to suggest, as Gillberg (7) did, that there was a connection between the extensive treatment with neuroleptics and the circumstance that these were seen in adult life by psychiatrists who had no particular knowledge of childhood autism. Conversely, the case records bear evidence of repeated discussions about the diagnoses and presentation in these patients and it is very obvious that, in the majority of cases, the psychiatrists were fully aware of the child psychiatric disease.

#### Psychiatric diagnoses in adulthood

It is of interest that 6 patients in the CA group and 1 patient in the AS group had at one time during the follow-up received a diagnosis of schizophrenia as described in ICD-8 (23). The adult psychiatric diagnoses on follow-up investigation were established on the basis of descriptions in the hospital case records. Where the AS group is concerned, our findings are in agreement with the observations of Wolff et al. (33) and Wolff and McGuire (34) that 'schizoid' children, who share many clinical features with Asperger syndrome often developed a schizotypal personality disorder as adults. We found that 1 patient in the CA-group showed unequivocal evidence of positive symptoms of schizophrenia. Additionally, 1 patient had complained of hearing voices, but had no other positive symptoms. The communicative speech of this patient was limited and therefore it is doubtful whether she was able to express her experiences. It would have been desirable to conduct a diagnostic interview to further substantiate that the patients with CA as adults had developed in the direction of a schizophrenic disorder.

Our findings are not different from the general view that the incidence of schizophrenia in people with autism is not higher than would be expected in the general population (11, 29).

In summary, this 30 years follow-up study of hospitalized CA and AS children shows clearly that in middle adulthood the CA group has a much poorer outcome regarding education, employment, autonomy, marriage, reproduction and the need for continuing medical and institutional care.



## Appendix

### Definitions

#### *Intellectual level*

Persons were grouped into four different IQ categories in agreement with the prepubertal test results: Severe mental retardation (SMR, IQ<50); mild mental retardation (MMR, IQ 51–70); nearly normal intelligence (NA, IQ 71–85); normal intelligence (A, IQ>85).

#### *Residence*

Psychiatric institutions are either psychiatric departments for chronic patients or psychiatric nursing homes.

Institutions for mental retardation are group homes for mental retardation (MR).

#### *Outcome*

The criteria recommended by Lotter (22) for assessing overall social adjustment are employed. Good outcome = normal or near normal social life and satisfactory functioning at school or work. Fair outcome = some social and educational progress despite significant or even marked abnormalities in behaviour or interpersonal relationships. Poor outcome = Severe handicap, no independent social progress. Very poor outcome = Unable to lead any kind of independent existence.

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