

INTERVENTION, TREATMENT AND CARE IN AUTISTIC DISORDER. CHALLENGING CASE REPORTS FROM NORTHERN FINLAND

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ABSTRACT

Objectives. Autism produces characteristic patterns of behaviour, and individuals with autistic disorder (AD) have a lot in common in terms of behaviour and mannerisms. Individuals with autism, however, also have their own overall personalities, which both underlie and interact with their autism. This article focuses on challenges of identifying AD and delivering appropriate services in face of long distances and limited resources.

Study Design. This study is a retrospective descriptive chart review and cases series. Hospital records and data on the treatment/habilitation status of 187 children and adolescents with autistic disorder aged 3-18 years were evaluated from Northern Finland.

Methods. Nine subjects, representing the age group of 9- to 17-year-olds, did not show any improvement on the Childhood Autism Rating Scale (CARS) and in the clinical examination during the follow-up period 1990-97. In this study, these children and adolescents with AD were evaluated more carefully.

Results. The treatment programs and therapies varied, depending on the availability of trained staff. There were various reasons for the absence of the most suitable treatment, or habilitation, at the individual level. The difficulties also varied over time and between individuals. In addition, after the follow-up period, four of the nine (55.6%) individuals showed more positive outcome when the level of autism had been taken into account in the planning of the intervention for, treatment and care of AD.

Conclusion. The possible reasons for poor outcome included the level of mental disability, impairments of speech and communication, lack of knowledge of autism at the municipal level, long distance to services, severe epilepsy, additional medical diagnosis, parental acceptance of the child's autism and late start of the intervention for, or habilitation of autism. (*Int J Circumpolar Health* 2005;64(1):65-76.)

Key words: Autism, Autistic disorder, Treatment, Habilitation, Education, Child

INTRODUCTION

Autistic disorder (AD), or childhood autism, is a neuro-developmental disorder diagnosable based on behavioural criteria reflecting an abnormal development of social interaction, communication and imagination (1, 2). Autism may co-occur with any level of ability, from profound general learning disability, to average, or even superior cognitive skills in areas not directly affected by the basic impairments (3). Autism is not a rare disorder, and more and more children and their parents are seeking treatment, care, habilitation and knowledge of AD. The prevalence of AD was reported to be in the range of 6-7/10 000 in Northern Finland in the late 1980's (4). According to more recent studies, AD occurs in 10-20 per 10 000 children (5-9), while the rate of autism spectrum disorders (ASD) may approach 0.6-0.9% of the population (10,11). In the age group of 5-7 years, the prevalence is reported to be as high as 20.7 (15.3-26.0)/10 000 in the northern parts of Finland (7).

After Leo Kanner's description of autism in 1943, the climate of opinion, especially in the USA, was heavily influenced by the psychoanalytical theory and very few of the therapists understood the neurological bases of autism. As a consequence, parents felt being blamed and autism was regarded as an emotional disorder without any neurological basis. The treatment of AD was also influenced by the psychoanalytic theory. The tide began to turn in the 1960s. The parents in the USA and UK rejected the idea that they were to be blamed for their children's problems. Also, some researchers proved that autism was a disorder of the developing

brain, mainly genetic in origin and part of a wider spectrum of disorders (12). In Finland, the tide began to turn in the early 1980s, and the first behavioural training program for individuals with AD was the Portage program, and other specialized programs, such as TEACCH and Lovaas, were adopted for use in the early 1990's in Northern Finland. Personnel in day-care centres, schools, hospitals and institutions, as well as parents, were trained to use these interventions in everyday life. The parental organization for autism in Finland also had an important role in launching the intervention and habilitation methods in the field.

The aim of this study was to identify the problems and challenges influencing the outcome in the intervention, treatment and care of AD. Another aim was to elicit reliable information for decision-makers and ideas for giving support and, because of better outcome, saving resources in the long run.

MATERIALS AND METHODS

The present survey was conducted in the primary and secondary catchment areas of Oulu University Hospital, Finland, where the total population of children was 152,732, representing the age group of 3- to 18-year-olds on the census day of 31 December, 1996. In addition to Oulu University Hospital, there are four central hospitals in the area, namely the Central Hospitals of Kajaani, Kemi, Kokkola and Rovaniemi. There are also central institutions for the intellectually disabled in Oulu, Kajaani and Rovaniemi in the defined area. 187 children met the full criteria for AD according to

the DSM-IV (1) and childhood autism according to the ICD-10 (2).

The data were collected from hospital records and from the records of the central institutions for the intellectually disabled. The cases selected have, at some point in their lifetime, used communal health services and, according to the hospital records, have been diagnosed as showing autistic behaviour. Each autistic child had been evaluated and assigned a diagnosis of autism based on the clinical judgement by an evaluation team, consisting of a child psychiatrist, or a child neurologist, a psychologist, a speech therapist and a physiotherapist. The final diagnoses had been made by child psychiatrists, or child neurologists (7). The data were collected in 1996-1997 and statistically analysed using the SPSS statistical software. The childrens' hospital records and all available information were re-evaluated through pregnancy to adolescence. Eight out of nine children and adolescents have also been followed by the author (MK) after the follow-up period and in 1999 a new project was launched in Northern Finland to support families, professionals and persons with autism spectrum disorders (ASD).

Intellectual functioning had been assessed with the Griffiths Developmental Scale, or the Wechsler Intelligence Scale for Children (WISC), by clinical psychologists (7). The level of intellectual functioning has been defined as the intelligence quotient (IQ, or IQ-equivalent) obtained with one, or more, standardised, individually administered intelligence test. The Childhood Autism Rating Scale (CARS) has been used to assess the severity of autism (16). If not previously

available, CARS analyses were made for the purposes of the present study based on all the available information. The scores indicating non-autism were < 30 points, those suggesting mild, or moderate, autism were 30-36, and those for severe autism were >37. The first CARS estimations were taken, or performed, at the age of 3 to 5 years. The latest CARS estimations were made in 1997. Improvement was determined as a change of autism degree to lighter classes, i.e. severe to mild, or moderate, or mild, or moderate to non-autism. In borderline cases, a score decrease of at least two points was also required for determining a state of improvement. Nine subjects out of 187 (4.8 %) did not show improvement on the Childhood Autism Rating Scale (CARS) during the follow-up period (17). In the present nine case studies, the children and adolescents with AD were evaluated more carefully.

Case reports

1. Nine-year-old girl

The first years of life revealed nothing special. However, language development was delayed, and the girl was referred to a hospital. At the early stage/phase, treatment and co-operation with the hospital failed. The family was very frustrated and depressed over the situation, and they moved to another city to get better treatment for their child. The child received speech therapy for many years. However, she was only enrolled in an AD-specific and structured program at the age of eight. At the age of nine, there are severe problems in communication and social interaction. She does understand some words, but still has difficulties in understand-

ing language, and these problems also make her learning difficult. The girl is often silent, withdrawn and depressed due to her several failures. Her intellectual functioning falls between mild mental retardation and mental subnormality. Recently, after the follow-up period, her level of autism was still severe but there is some hope of improving the situation, because the child has got a specially structured program suited to her abilities.

2. *Ten-year-old boy*

Delivery was normal, but the newborn had a big head (circumference +2 SD) and hyperbilirubinaemia (279mmol/l), which normalized after blue light therapy. The parents noticed that, after a normal early development, at the age of two, following the birth of his younger sister, the boy's development began to decline. His intellectual functioning suggests moderate mental retardation. The diagnoses of AD and mental retardation were established at the age of three. Since the boy does not speak, communication and interaction has been very difficult. He has had several therapies (music, speech and riding therapy). However, a structured daily program and a communication-based program aimed at his level were not available at school up to ten years of age, and are still lacking at home. The father has not accepted his son's mental retardation and autism.

3. *Ten-year-old boy*

Epileptic seizures were diagnosed at the age of two, and autistic symptoms were also suspected. However, AD was not diagnosed until the age of six. The level of intellectual functioning indicates moderate mental retardation, but it is

very hard to estimate the real functioning level, because of the severity of the autism. The boy does not speak and understands language very inadequately. He is very restless and needs to be looked after constantly in daily life. Epileptic seizures have also impaired the situation. After the diagnosis of AD, the boy was given speech therapy and music therapy. Mental retardation makes his habilitation very difficult. There was a structured daily program and a communication-based program to suit his level at the age of six. At the school, knowledge of autism is poor, but the school personnel have now started to acquire knowledge and they receive education concerning autism. In fact, after the follow-up period in 1997, and after the instruction about the structured daily program, the boy's behavioural problems have become somewhat alleviated.

4. *Twelve-year-old boy with autism*

Due to severe toxemia, caesarean section was performed at the 35th week of pregnancy. The infant's birth weight was 2470 g and Apgar scores were 6/7/9. After the first epileptic seizure at the age of three, his development has not been 'normal'. However, there were some notes in the hospital records even before the first epileptic seizure, suggesting that the child's social behaviour was odd, and that his behavioural problems at home were difficult and ritualistic. His level of intellectual functioning is subnormal. Due to learning problems, he attends a school for the mentally retarded. The boy has had speech therapy and occupational therapy since the age of eight, but only for a couple of hours per week. There is also a lack of professionals qualified to work with autistic

children in the local community. Habilitation at school and at home has not taken into account the boy's autism. The boy is very rigid in his behavioural routines, and any change may cause a violent temper tantrum. Both at school and at home, the people dealing with the boy have failed to realize that a structured environment and a daily program are very important to him, and that traditional handling does not help the situation.

5. *Twelve-year-old boy*

He was small for his gestational age, weighing 2500g (at a gestational age of 38 weeks and 5 days). His Apgar scores were 5/6/8. During the neonatal period, he had low glucose levels, was icteric (hyperbilirubinaemia level 277 mmol/l) and was given blue light therapy. At the age of three, he was diagnosed with autism and moderate mental retardation at a central hospital. However, no specific therapies, or strategies adapted to his condition were started until the age of eight (speech therapy), because the parents did not believe that their child had autism and mental retardation (moderate mental retardation). Knowledge of autism in the local municipality was also poor and, consequently, possibilities for habilitation for autism were also lacking. At the age of ten, he received his first specific treatment for autism, was provided a structured daily program and received consultatory help from a specialist in autism. His teacher also received education on how to work with a child with AD. After the follow-up 1997, the outcome is more positive, although communication is still a problem: the boy does not speak and understands only simple spoken sentences.

6. *Thirteen-year-old boy*

At the age of two, the boy spoke long sentences, but, after that, his speech deteriorated and he now lacks communicative speech. His intellectual level indicates mild mental retardation. The diagnosis of autism was made at the age of three and, at the age of four, he started speech therapy. There have been serious sleeping problems, and traditional sedative medication has not helped the situation. His behavioural problems increased every time he was placed in a new foster family during early childhood. Losses might have been traumatic experiences and influenced his life as well as his outcome. In addition, there has been a lack of knowledge of autism at the local municipal level. A structured daily program and a communication-based program for his level were lacking until the age of thirteen, when he was enrolled in a TEACCH-based intervention and a communication-based program using pictograms. His behavioural problems persist at home, but no longer at school.

7. *Thirteen-year-old boy*

An unknown hereditary syndrome has caused severe mental retardation, which was the primary diagnosis, and his AD was not treated until recently. During his first year of life, the boy had physiotherapy for delayed motor development and, at the age of three, he started speech therapy, because speech was lacking. Communication is still at a low level, and it is very hard to understand his interactive messages. Actually, only the parents can understand his communication. Persistent sleeping problems, lack of communication and restlessness are the most serious

problems today. The outcome is further impaired by severe epilepsy. The level of autism is still severe.

8. *Thirteen-year-old boy*

The boy's mental retardation was detected at the primary health care clinic at the age of five. His brother also has mental retardation and autism, which suggests the presence of an unknown hereditary syndrome. At the age of six, he started speech therapy. The diagnosis of AD was made at the age of nine and, after this, he was put on a specific treatment program. Local knowledge of autism has been poor, which has prevented the identification of autistic features and the introduction of treatment and interventions for AD. He has mild mental retardation, and the severe epilepsy impairs the situation and makes his habilitation even more difficult. His social communication is poor, and daily behavioural problems are still present.

In fact, after the follow-up period in 1997, after being provided a structured (TEACCH-based) program at school, his behavioural problems have decreased in adolescence. Today 2004, he has some communicative speech and understands simple sentences.

9. *Seventeen-year-old boy with autism*

At the age of one, the boy went through heminephrectomy. After the operation, his development began to decline. Autism was diagnosed at the age of nine. The boy's intellectual functioning indicates moderate mental retardation, but it is obvious that the test results cannot be taken at their face value as, according to the psychologist's opinion, the results could be close to the normal level if the boy really wanted to use his intellectual capacity. The lev-

el of autism, as assessed by CARS, still indicates severe autism. In addition, the severe anxiety attacks and major behavioural problems have been extremely difficult to handle. Very severe behavioural problems appeared at school, and the ordinary school resources were not sufficient in his case. At the age of nine, he had some music therapy, but the structured program was not used effectively until the age of ten. Many years have been wasted due to inadequate diagnosis and treatment.

RESULTS

According to standardised, individually administered intelligence tests (18), the study subjects' general levels of intellectual functioning, or the intelligence quotient (IQ, or IQ-equivalent), were between mental subnormality and moderate mental retardation. In most cases, verbal and non-verbal intelligence were not separately reported in hospital records. Six of the nine individuals had severe impairments of speech and did not communicate verbally. The verbal abilities of all nine challenging cases showed no positive change during the follow-up.

Except in one case, other therapies were started before specific efforts at the habilitation of autism. In three cases, epilepsy also interfered with the treatment of autism. In six cases, there was a lack of knowledge of autism at the municipal level. In the case of five individuals with AD, there were additional medical diagnoses (excluding epilepsy); two cases of encephalitis, one short stature, and two disorders of unknown genetic origin). In three (out of nine) families, both parents had refused to accept their child's AD and disability. The aver-

age of diagnosis for the children with AD was 6.1 years (min 3 and max 11 years). The mean age of starting autism-oriented habilitation in line with the TEACCH, Lovaas, or Portage methods in the total group of 187 individuals with AD was 4 years and 3 months, while in the group presented here, the corresponding age was 9 years and ten months. An even greater difference was seen when the whole group of 187 was divided into two categories and compared in the youngest age group of 5-7 years, where the age of starting habilitation was 3 years and 3 months, and in the oldest age group of 15-18 years, where the mean

age of starting habilitation was 6 years and seven months.

Six years after the follow-up period, five out of nine (55.6%) participants (see cases 1,3,5,6,8) showed a more positive outcome when the level of autism had been taken into account in the planning of intervention, treatment, care and habilitation. The average distance to the nearest central hospital was 80.9 km (min. 5 km and max. 390 km) in the whole group of 187 individuals with AD and 96.7 km (min. 10 km and max. 280 km) in the target group. The basic clinical findings of the nine individuals with AD are presented in Table I.

Table I.

Basic clinical data on the nine individuals with AD.

Characteristics										all 187
Gender and age (years)	1. F(9)	2. M(10)	3. M(10)	4. M(12)	5. M(12)	6. M(13)	7. M(13)	8. M(13)	9. M(17)	%or mean
M/F										79.1/20.9
Birth order in family	1/1	1/3	4/4	1/3	1/1	2/3	2/2	2/3	2/3	-
Normal pre- and perinatal period	+	-	+	-	-	-	-	+	+	-
Apgar points	9/9/9	9/10/10	9/9/10	6/7/9	5/6/8	10/9/9	9/9/9	9/9/9	10/10/10	-
Birth weight (kg)	3.2	4.3	3.6	2.5	2.5	3.7	3.6	3.3	3.3	3.3
Diagnoses of AD (years)	3.0	3.0	6.0	7.0	3.5	3.5	11.0	9.0	9.0	4.1
Epilepsy and seizures	-	-	+	+	-	-	+	+	-	18.2 %
CARS points (first/follow-up)	44/48.5	32/39	40/38.5	37.5/37	42.5/42.5	45/44	43.5/44	38.5/37	39.5/42	36.0
Mental retardation	Ms	Mo	Mo	Ms	Mo	Mi	Mo	Mi	Mo	51.3 %
Impairment of ambulation/ Vision/ hearing	-	-	-	-	-	-	-	-	-	3,7/7.4/1.6 %
Impairment of speech	+	+	+	-	+	+	+	-	-	42.3%
Abnormal responses to sensory stimuli	-	+	+	-	+	+	+	-	-	74.3%
Additional medical diagnosis (e.g. epilepsy)	+	-	-	+	+	-	+	+	-	19.8%
Start of habilitation of autism (years)	8	10	6	12	10	13	11	9	10	4.3
Start of other therapies (years)	3	4	6	8	8	4	1	6	9	4.2
Living	U	R	R	R	R	U	U	R	U	60.8%
Nearest central hospital (km)	10	40	200	140	50	40	10	280	100	80.9

F(Chronological Age) = Female; M(Chronological Age) = Male

+ = well documented, clearly holds; - = no convincing evidence

U = urban area; R = rural area

Ms = Mental subnormality (IQ level 70-85); Mi = Mild mental retardation(IQ level 50-55 to 70);

Mo = Moderate mental retardation(IQ level 35-40 to 50-55)

CARS classification; < 30 points = non autistic, 30-36 points = mild, or moderate autism; 37-60 points = severe autism

DISCUSSION

In the follow-up studies from the 70's to the early 90's, only 5-15% of individuals with AD had a good outcome with a nearly normal, or normal, social life and acceptable functioning at work, or school, despite certain difficulties in social relationships and oddities in behaviour (19-22). Cognitive ability, the level of mental retardation and other comorbidities, including medical syndromes, neuropsychiatric disorders and epilepsy, are important prognostic factors (14, 23-25).

The average age at diagnosis of children with AD was 6.1 years in this study. In studies from the UK and USA, the corresponding average ages were 5.5 and 3.9 (11, 22). Early diagnosis, before the age of 3 years, was rare in this study, but enabled the initiation of habilitation of autism at an early age. This was also one factor that obviously influenced the outcome in this study, as behavioural treatment may produce long-lasting and significant gains for many young children with autism (17, 22, 26). Unfortunately, the knowledge of autism in some municipalities in Northern Finland was not good in the 80's and early 90's.

The interpretation of this study is limited by the fact that the results are based on the hospital records, which may vary in the main focus of the reports. In addition, the CARS, employed as a rating instrument, might exhibit considerable variation and error across ratings and raters. The time intervals between assessments also influence the outcome measurements and the CARS instrument might not take into account enough of the different developmental ages. The small size of the sample may fail to reveal other circumstances influencing

the outcome and, thus, the interpretation of the results should be made with caution.

The TEACCH, Lovaas and Portage projects have developed principles of special treatment, care and habilitation of children and adolescents with autism (27-29). The age at which treatment begins is one factor that appears to influence the outcome (17). There is evidence to show that the intervention programs that begin at an early age, between the age of 2 to 4 years, are most effective (24,30). However, the number of cases involved in evaluative studies of early behavioural/educational interventions remains very small, and blinded, randomised and controlled trials are virtually non-existent (24). It also seems that the establishment of appropriate management strategies in the early years can help to minimise, or even avoid, many behavioural problems (17, 28, 30, 31, 32). In fact, after the follow-up period in 1997, and after the implementation of a structured intervention program at school and at home, many subjects had fewer and less severe problems in adolescence. It should be kept in mind that there is always hope to improve the situation, even when there has been no specific habilitation of autism in childhood. The parental counselling provided locally has helped families to cope with their everyday life. In fact, a new project was launched in Northern Finland in 1999 to support families, professionals and persons with autism spectrum disorders. The detection and understanding of AD in Finland was also improved by the specialised instruction offered to the staff of Oulu University Hospital via interview methods in 2001 and 2003. The methods were the Autism Diagnostic Interview Schedule – Revised (ADI-R) for interviewing the parents (about the child) and

the Autism Diagnostic Observation Schedule (ADOS) for observation of the autistic persons themselves.

In this study, six of the nine children and adolescents with AD had severe impairments of speech and their ability to communicate verbally was poor during the follow-up period. It has been estimated that around half of all children with AD fail to develop functional speech (33). Follow-up studies indicate that most children with AD who have not developed useful speech by the age of 6 or 7 years will remain very impaired in their ability to communicate verbally (20, 34, 35). Challenging behaviours often result from the child's fundamental difficulties in communication and social understanding, or from the ritualistic and obsessional tendencies that are characteristic of autism (22). The developmental course of linguistic and communicative abilities in children without major disabilities has its roots in pre-verbal communication in infancy, and even new-born babies demonstrate social intent and active interest in communication (36).

Almost half of individuals with autism are mentally retarded and do not develop any spoken language at all, whereas the other half displays various linguistic deviancies, such as pragmatic deficiencies, echolalia and idiosyncratic vocabulary (13). An IQ below 50 around school age predicts severe restriction of social and adaptive functioning in adult life (14). The dysfunction in language comprehension and speech is likely to lead to a specific impairment in social relationships and imaginative play (15). Even though an IQ over 50 around school age predicts a good outcome in social and adaptive functioning in adult life, difficulties may occur in habilitation, even in

the well-functioning group of individuals with AD, if autism has not been taken into account (see case 4). In six cases, the lack of knowledge of autism at the municipal level also influenced the outcome. In some cases, the professionals (teachers, psychologists, therapists, or medical doctors) are well-educated and have a long working experience (but not in autism) and may, therefore, be reluctant to ask for outside help. However, one should not hesitate to admit a lack of complete knowledge of the wide range of autism spectrum disorders.

It is now well established that early intervention, care and treatment, appropriately adapted to each individual child's pattern of strengths and weaknesses, can significantly help to minimise, or avoid, problems and to ensure that everybody is able to develop their existing skills to the full extent. Training studies using computers have also had promising effects on autistic children's communication, reading and language skills (37). Facial affect recognition and computer-based interventions also yielded promising results in a recent study (38). Unfortunately, computer-based interventions were not a well-known method in this group of nine children with AD in the 1990's. In addition, the lack of Finnish-language computer programs and skilled teaching professionals has resulted in the scant use of computer-based interventions in Northern Finland.

Three families who participated in this study had not accepted their child's AD. This had caused the families to feel sorrow, anxiety and insecurity and also to refuse to adjust to the treatment, or intervention program of autism for many years. Coping with a child who has a chronic illness, or a severe disorder, is a highly individualized process, and there is evi-

dence to suggest that some families may never fully adjust to the situation (39-41). The family's ability to acquire and allocate resources to meet demands is a critical aspect of adjustment and adaptation. Conversely, poor outcomes increase the demands and may lead to maladaptation (42-44). Parents are often elighted to meet other parents of children with AD and to find that these children have a lot in common in terms of behaviour and mannerisms. Meetings with other parents and individuals with ASD should also be sponsored more by municipalities and hospitals, though this has not been considered as therapy in the traditional sense. The essential question should be stated and also studied more specifically: what really helps in the sense of habilitation and coping with ASD. Parents are usually very happy when they get some help for their children, and they do not even know of any other possibilities. Many parents admit to seeking out alternative treatments, because they are simply unable to get the information they need about locally available facilities. Therefore, we should encourage the professionals working in this field to guide parents and also to seek for the best solutions through consultation if their own knowledge of ASD is inadequate.

Previous studies of gender and autism have shown girls with autism and mental retardation to be more severely affected than boys, with regard to both the level of intellectual functioning and the overall measures of brain dysfunction (11,45). This was not true of the girl in this study, though her level of autism was most severe. However, the social impairment in autism affects almost every aspect of the child's functioning, regardless of his, or

her, intellectual ability. The long distances in rural areas are a big problem in the availability of treatment, care and habilitation (Table 1). The treatment programs and therapies varied in the study area, depending on the availability of trained staff. Though many children had some therapy (usually speech, or physiotherapy) at an early age, it was not sufficient to alleviate the severity of autism. Other aspects of communicative development were also very poor in these cases. In Northern Finland, the lack of professionals also had a paralysing effect on the quality of habilitation. These are important factors when considering the need to finance the intervention, treatment and care of AD. In the northern parts of the globe, long distances from home to services constitute a major problem, which is being increasingly solved by the use of telematics. In the case of autism, this might essentially help health care and education personnel by providing opportunities for consultation. Local social, public health and educational administrators would be able to use this information, which would be very valuable for assessing specific needs and financing.

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