What is Important for Autistic Adults to Become Independent or Self-supporting ?

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Abstract: Thirty autistic adults (24 males and 6 females) have been observed continuously from childhood to their present state. The results were as follows : the social outcome now is that most of them were educated through high school age and eight of them are independently self-sufficient or expected to be so. The results were much better than in previous reports. The intellectual level and the adaptive one were used to evaluate their developmental level. On both levels about 60% were in the "poor" group. Even those who had a good intellectual level were not always good at adapting. But those who were not in the "good" intellectual level can be in a good adaptive level. This discrepancy reveals the difficulty in predicting the development of autistic people. Clinical symptoms undergo various changes during the patient experiences in his/her life-long development. Autistic people are confronted with the growing pains or frustrations of adolescence. The factors important for autistics to be independent are discussed from the view point of their development from adolescence to adulthood. They should be given help to enable them to cope with the developmental issues of adolescence and adulthood.

Keywords: autistic adult, adolescent crisis, employment, self-support

Introduction

More than 30 years have passed since the first case of early infantile autism was reported in Japan in 1952,[11] which was 9 years after Leo Kanner[3] proposed the syndrome of early infantile autism. In Japan, in the 1950's and 60's, the treatment for autistic childen was mainly play therapy. However in the 1970's and 80's, autistic children have been given intensive education in public elementary schools, in special educational programs and integrative programs. Through intensive therapeutic approaches, autistic children's developmental courses have improved. But many follow-up studies have shown that in adulthood they are not in good clinical condition.[2,5,6,8,9,12]

In the city of Fukuoka. Japan, we began treating autistic children in a group therapeutic "Saturday Class" setting with volunteers under the supervision of psychiatrists.[7] Soon after that, a special program was introduced into selected public elementary schools. Most of those who were treated in the 1970's, are now in adulthood.

We examined thirty autistic adults, who have been observed continuously from childhood to the present time, taking into consideration their states of mind and their lifelong development. We examined their developmental couse and developmental level, their present clinical symptoms and their unique problems in adulthood.[4] This paper, by investigating the living and working conditions of employed autistic adults, attempts to ascertain what is most important for autistic

adults to become independent or self-supporting in Japanese society.

Subjects

The subjects were autistic adults, who were observed continuously from childhood to adulthood. As of April of 1986, they are now more than 20 years old. We examined their present developmental level directly. The subjects who have died during the course of the observation have been excluded from the data. There are thirty subjects; 24 males and 6 females (4 : 1) with a mean age is 22.5 years (S. D.=2.8) (Table 1). The youngest being 20 years old and the oldest 29 years old.

Table 1 SUBJECTS

Sex \ Age	20~21	22~23	24~25	26~27	Years 28~29	Total
Male	12	8	0	3	1	24(80%)
Female	3	0	0	1	2	6(20)
Total	15	8	0	4	3	30(100)

Present social outcome

The present social outcome is as follows (Table 2). Seven are employed, which is 23 % of the total, a relatively high employment ratio. One who is undergoing training at an occupational center, is expected to be able to get employment in the near future. Three are in a sheltered workshop. Nine are in special care units for the mentally handicapped. Four are in a specialized unit for autistic people, which was founded this spring by their parents. Three are hospitalized. Three are cared for at home only. Table 3 shows the mentality, education, occupation, income and residence of seven employed autistic adults. Some are mildly or moderately mentally retarded, but they are within a good adaptive level. Though they are employed, they receive a low income, about 50,000-60,000 yen (or about 337 US$) a month. This reveals their low assessment in society.

Table 2 SOCIAL OUTCOME AT PRESENT

Social outcome	Male	Female	Total	Percent(%)
Employed	6	1	7	(23%)
Vocational training center	1	0	1	(3)
Sheltered workshop	2	1	3	(10)
Specialized unit for autistic people	4	0	4	(13)
Special care unit for mentally handicapped	7	1	8	(27)
Hospitalization	2	1	3	(10)
Home	2	2	4	(13)
Total	24	6	30	(100)

Table 3 SOCIAL-ADAPTIVE FUNCTIONING OF SEVEN EMPLOYED AUTISTIC ADULTS

Case	Age	Sex	IQ	Education	Employment	Monthly income (Yen**)	Residence
1. Y.H.	29	male	normal	Technical high school	Japanese cake maker	5-60,000	with parents
2. Y.S.	27	female	borderline	Special school*	Japanese futon maker	5-60,000	with parents
3. H.O.	26	male	normal	High school	Bus guide (part-timer)	7-80,000	with parents
4. K.T.	23	male	moderate MR	Special school*	Laundry	5-60,000	with parents
5. K.S.	22	male	mild MR	Special school*	Laundry	5-60,000	with parents
6. J.K.	22	male	mild MR	Special school*	Laundry	5-60,000	with parents
7. T.M.	20	male	normal	Special school*	Hakata-doll maker	5-60,000	with parents

* Special school is one for the mentally disturbed.
** About 160 Yen is one US$

Present developmental level

The patients' social adaptability is not always equal to their intellectual level. Thus we examined their developmental level in two modalities, the intellectual level and the adaptive one. Table 4 shows that in the intellectual area, there are 7 cases that fall into the good-group classification; there are 5 cases that fall into the fair-group; and then 18 who are in the poor-group. In the adaptive area, 9 are in the good-group, 2 are in the fair-group and 19 are in the poor-group. Both on an intellectual and adaptive level, about 60 % of them are in the poor-group. Table 5 shows the correlation between the intellectual level and the adaptive one. Even those who are at a good intellectual level are not always in a good adaptive one. But those who are not at a good intellectual level can be in a good adaptive level. This discrepancy reveals the difficulty in predicting the development of autistic people.

Table 4 DEVELOPMENTAL LEVEL AT PRESENT

Developmental level	intelligence	Adaptability
Good	7 (23%)	9 (30)
Fair	5 (17)	2 (7)
Poor	18 (60)	19 (63)
Total	30 (100)	30 (100)

Table 5 CORRELATION BETWEEN INTELLIGENCE AND ADAPTABILITY

Intelligence \ Adaptability	Good	Fair	Poor	Total
Good	5	2	0	7
Fair	4	0	1	5
Poor	0	0	18	18
Total	9	2	19	30

Intellectual level and present clinical symptoms

The subjects' clinical symptoms are examined at their intellectual level. The results are shown in Table 6. Hyperkinesis decreases with intellectual level. But akinesis has become difficult problem in its place. Aspontaneity is one of the most serious problems in autistic abults. Of the group, seven have epileptic seizures, which are all grand mal types of epilepsy. Most of the seven exhibit severe mental retardation. The age of onset is 10 to 20 years of age.

There are various neurotic symptoms, for example: pollakisuria, obsessive ideas and phobic reaction. Tic seems to be absent in autistic adults. There are some psychotic symptoms, such as monologue, drawn laughter, phantastic ideas, oddness and delusions. Their delusions are the idea of refenence or hypochondriacal ones. They respond well to drug treatment.

Psychosexual development is very poor. The subjects are little interested in sex, whether it be the opposite sex or the same sex, and are indifferent to the changes of their body image. Many show open masturbation. Because they have difficulty relating to others, they cannot become involved with sex.

The most unchangeable clinical symptoms are obsessive tendencies and poor emotional expression, or autistic features. These sympoms, combined with the autistic's inability to experience emotional rapport with others, are the basic problems unique to the autistic patient.

To summarize the changes of clinical symptoms in adulthood, first, a decrease in hyperkinesis must be noted. Aspontaneity will follow as a result. This is mainly related to the maturation of the brain, a biological factor. In addition, epileptic seizures occur in about 20% of autistic adults. This ratio is consistent with other reports. Secondly, various neurotic and psychotic symptoms prevail. Autistic people are confronted with the growing pains or frustrations of adolescence. In addressing these problems, they usually respond with various neurotic or psychotic defense mechanisms. These symptoms are strongly related with many psycho-social factors. Thirdly, some symptoms very seldom change. Obsessive symptoms and poor facial expressions or autistic features prevail; these are closely related with "autism". They con-

Table 6 INTELLECTUAL LEVEL AND PRESENT CLINICAL SYMPTOMS

Symptoms	Intellectual level (IQ)				
	Normal n= 7	Mild MR n= 8	Moderate n= 2	Severe n=13	Total N=30
epilepsy	0	1	1	5	6 (20%)
panic	0	4	0	9	13 (43)
self-destructive behavior	1	4	1	10	16 (53)
injurious behavior	0	3	0	5	8 (27)
aspontaneity	0	2	0	10	12 (40)
poor facial expression	4	8	2	12	26 (87)
open masturbation	0	2	0	10	12 (40)
interest in heterosexual relationship	3	2	1	1	7 (23)
sameness	1	4	1	12	18 (60)
hyperkinesis	0	0	0	3	3 (10)
autistic feature	0	8	1	12	21 (70)
pollakisuria	0	1	0	1	2 (7)
obsessive behavior	2	5	2	12	21 (70)
obsessive idea	5	2	1	2	10 (33)
phobia	1	1	1	3	6 (20)
tic	0	0	0	0	0 (0)
monologue	0	4	1	6	11 (37)
drawn laugher	0	3	1	4	8 (27)
phantastic idea	1	4	1	1	7 (23)
oddness	1	1	0	0	2 (7)
delusion	1	0	1	0	2 (7)
hallucination	0	0	0	0	0 (0)

tinue throughout life. Clinical symptoms undergo various changes as the patient experiences his/her life-long development.

Autistics and adolescent crisis

When we discuss autistic social independence, the most important issue is how the subjects overcome adolescent crises. The first crisis comes during the "gang" age. In pre-adolescent age, one develops friendship with schoolmates. but autistics cannot easily socialize, because of their difficulty in relating to others. This is a result of their inability to recognize social awareness. The second crisis has to do with body image changes. Autistics have disturbances of body, schema, so that they cannot easily accept the changes of their body. They cope with the defense mechanism of rejection or denial. The third crisis has to do with the acquaintance of self-awareness or feeling of identity. Autistic adolescents have difficulty in differentiating between themselves and others, so they cannot reach ego fulfillment by identifying through modeling. Instead they imitate life styles dogmatically and faithfully. The patients are too dependent on the sources of their ego-ideal. Strong ego-ideal is the vehicle toward their social identity. They have a basic amenability to parent and teacher authority, so they have a tendency to live a dogmatic life style, which in turn builds social identity. The last crisis is one of the most important issues, which is their psychological separation from the mother and eventual individualization (second individuation).[1] In Japan it is said that fathers are occupied with work and mothers are occupied with the care of their children. It is the same with families of autistics in Japan. Even in adolescennce they are too close emo-

tionally to their mothers, which hinders them from reaching individualization socially. Autistics have a desire to be independent of their parents, just like other children. Taking this into consideration, we should help them on that road to independence or semi-independence.

What is important for autistic adults to become independent ?

We have discussed the development of autistics cross-sectionally and longitudinally. Now we will discuss what is important for them to be independent, examining the employed autistic adults.

Case 1 : J. K., 22 years of age, male.

The patient was the full-term product of an uneventful pregnancy and delivery. Physical development was good in infancy and he did not resist separation from breast-feeding, which disappointed his mother. Also, he did not cling to her when she put him on her back. This worried her because her maternal needs were not being satisfied. At one year of age, he started uttering a few words : "Papa, Mama" et cetera, but a few months later they disappeared. He was sensitive to noise, so he could not sleep in the daytime. He was hyperkinetic, so it was dangerous to leave him alone. At three, he was diagnosed as suffering from early infantile autism after being referred to a university hospital. He went to Tokyo for special care, because there was no special care service for autistics in Fukuoka in those days. In Tokyo at five, he began to utter some phrases from TV commercials. At six, he entered a normal class of a public elementary school. At nine, his family returned to Fukuoka. At eleven, his teacher was so punctuality-conscious that he blamed the patient for being late for school. He and his mother became too sensitive and irritable to sleep at night. Both of them became neurotic and unstable. At 13, he was admitted to our hospital. His parents were taught the importance of physical affection while bringing him up, and it affected him to the extent that he overwhelmed others with his affection. His habit of kissing others did not disappear when he reached adolescence. Our nursing staff could not accept his need to kiss them. Their rejection caused panic behavior on his part. Haloperidol acted upon his temper tantrum. He gained weight and his obsession with kissing weakened. At 16, he was accepted into a specialized school for the mentally disturbed. He took part in a vocational program for high school aged adolescents which gave them special skills training. At this stage of development he disliked his mother's touching him. His mother felt lonely. Soon after she had her second baby. The second experience of mothering encouraged her and made her self-confident as a mother. She became emotionally stable. The patient, in turn, wanted to act his age, and not play like a child. At 19, he was employed at a laundry store. His job was to classify the laundry according to the serviced shops. He made no classification errors, and his employer valued him highly. When he got his wages for the first time, he gave his father some money for his own use and gave his mother ten thousand yen living expenses. It may be assumed that he received high self-esteem as a result of being self-supporting. His only hobby was traveling on trains by himself. Whenever he traveled, he brought his family and his co-workers souvenirs.

His mother's having a new baby led him to be psychologically separated from his mother in mid-adolescence. Getting a job and succeeding at it made it possible for him to be self-confident and self-supporting. He attained a good adaptive level beyond expectation.

Case 2 : T. H., 29 years of age, male.

The patient was the full-term product of an uneventful pregnancy and delivery. At three years of age, his hyperkinesis, restlessness and gaze aversion caused him to be referred to a mental hospital. He was suspected of having a childhood schizophrenic disorder. He received little treatment at that time. He entered an elementary school, but did not play with his schoolmates and was always isolated. He gradually calmed down naturally and passed his time by playing with and manipulating mechanical gadgets.

After graduating from technical high school, he entered the Self-Defense Forces of Japan,

He obtained excellent results from the Morse code signals test in his entrance examination. He did not get along well with others and saved most of his salary. As a result he accumulated three million yen (or 17,000 US$) in four years. After that, he got a job as a dish-washer at a restaurant. He worked as hard and as steadily as he had worked in the Self-Defense Forces of Japan. He saved one million yen in only one year and a half. But at the age of 24, he became too busy during the Christmas season to have a holiday. He got so tired that he became restless and psychotic. He uttered to himself and smiled a forced smile. He returned home very late and stopped praying at the family Buddhist altar, and he also stopped visiting the family grave. He became obsessive with using the toilet countless times a day. His parents brought him to a mental hospital. He was hospitalized for four months and recovered quickly. After various interviews with him, the reason why he had experienced a psychotic breakdown became clear. At his workplace, there had been a lazy fellow worker. He had been truant often. The patient was asked to work instead of him on his holiday. He could not refuse and suffered fatigue as a result. The patient charged that the fellow worker was lazy. This was a direct trigger for his maladjustment. But his history, since childhood, of obsessive behavior with a tendency to maintain "sameness" was seen to play a large part in his action. It became clear during his treatment that when he became anxious that his obsessive behavior pattern might be interrupted, he was forced to say something to the other workers in the defense of that pattern.

This patient was at a good intellectual level and adapted at a good level. He steadily adapted, but was overly zealous with things or details to the extent that he later suffered various consequences.

Now we will discuss what is important for autistics to be self-supporting in adulthood.

1. They might have a strong desire to work, so we should give them the chance to do so. They are often placed in low self-esteem situations because of their learning disabilities and their difficulty in socializing. They might not be able to obtain high self-esteem until they begin to work in adulthood. Concerning their vocations, we should help arrange work for them according to their mental and behavioral characteristics. Since obsessiveness is a characteristic of their life style, we should point them into a direction of work in which their obsessiveness would be a positive quality.

2. Over-adaptation might cause maladjustment. As illustrated in the latter case, autistics cannot work with flexibility, and become obsessive with the routine of their life styles, which might lead to maladjustment. We should recognize this obsessive tendency in order to better understand and help the autistics in the work realm. If this can be done, then psychotic breakdown can more likely be prevented.

3. Because of their clumsiness it takes great patience on the part of the autistic to acquire skilled techniques on the job.

4. Their inability to communicate, as well as their awkwardness with interpersonal relationships, should be taken into account. They should be offered simple physical work, since they have a handicap in communicating verbally. Too close contact with others should be avoided.

5. The autistic, like most other people, needs relaxation time. Thus, cultivating a simple hobby or pastime is of great importance. Hobbies, such as collecting things or redundant writing, can be continued to and throughout adulthood. How to play and what to enjoy are very important for their mental state.

We have discussed what is important for them to be independent from the view point of their development from adolescence to adulthood. We should try to help them cope with the developmental issues of adolescence and adulthood.

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