

The Needs of Parents who have Children with Autism Spectrum Disorder : Interview Survey in Japan

Michiko Araki¹ • Yoko Arai² • Hozumi Araki² • Yoshiaki Takeuchi²

Asuka Maeda² • Yohei Inoue³ • Zhang Rui² • Huang Xin Yin⁴ • Nguyen Thi Hoang Yen⁵

Introduction

In this study, the needs of parents who have children with Autism Spectrum Disorder (ASD) were investigated from July to September of 2010 in Japan, following a pilot survey conducted in March of 2010. The results of the pilot survey were reported at the “Fifth Seminar on Therapeutic Educational Programs for Children with Developmental Disorders in East Asia” held in Shanghai in June of 2010 (Arai and Araki, M. 2010). The results of the study were also reported at the “Sixth Seminar on the Development of Therapeutic Educational Programs for Children with Developmental Disorders in East Asia” (Araki, M. and Arai, 2010). As a control group we also collected data using the Life-Line Interview Method from parents who had typically developing children to compare with the data from parents who had children with ASD in order to clarify the specific needs of parents of children with ASD. The results of this survey were presented in a symposium at the 49th General Meeting of the Japanese Special Education Association held on September 24, 2011. We planed to present the findings of our comparative research in postersession at the 23rd General Meeting of Japanese Society of Developmental Psychology held on March 10, 2012 (Araki, M., Arai et. al., 2012). A portion of this research is presented in this report.

¹ Osaka Women's Junior College

² Ritsumeikan University

³ Nara University of Education

⁴ Suzhou University

⁵ Vietnam National Institute of Educational Science

1. Purpose and Methodology

1) Purpose

The overall purpose of this study is to identify the needs of parents who have children with ASD in several East Asian countries; Japan, China and Vietnam. A series of studies have been conducted across these countries and a certain amount of quantitative data is currently available. Qualitative data on the needs of parents who have children with ASD, however, is still limited. In order to further identify the needs of parents who have children with ASD, qualitative data on subjective opinions and responses from parents are required. Therefore, in this study we conducted Life-Line Interview Method interviews with both parents who have children with ASD and parents who have typically developing children (the control group) and semi-structured interviews with parents who have children with ASD. We compared the results of the Life-Line Interview Method interviews conducted with both groups of parents. The Life-Line Interview Method (LIM) is an effective means to represent the emotions of participants. The LIM contains a standardized framework with which we were able to compare the data in all three countries. The LIM has been used in studies involving the dynamics of the development of the elderly from a psychological standpoint (Schroots, 2004) or the reflection on the patients (Hirano, 2009). The results of the LIM reveal the life perspectives of an individual according to his/her life events. In addition to the LIM, we also used semi-structured interviews to examine the emotions described by parents who have children with ASD. The data from both the LIM interviews and semi-structured interviews can be used as qualitative data for further comparison across the three countries.

2) Methodology

(1)Participants Twelve parents who had children diagnosed with ASD and nine parents who had typically developing children with (the control group) participated in this study.

(1)-1 ASD Group

Among the twelve participants who had children with ASD, eleven of them belonged to the same parents' association. The ages of the children at the time ranged from seven to thirteen (from the second grade of elementary school through the third grade of junior high school). Eight of them had children who were attending ordinary classes (two of whom were enrolled in junior high school), two of them had children in special support classes (one of whom was enrolled in junior high school), and two of them had children in special support schools.

This study included data was collected from three participants as the pilot study in May of 2010, and we collected data from nine other participants between July and September of 2010.

Interviews were conducted at Ritsumeikan University, the interviewer's residence, the participant's residence, or the room of a public hall. The duration of the interviews ranged from ninety minutes to two hours per participant. The interviews were conducted with one interviewer and one participant, or one interviewer with two observers and one participant. Arai, Araki, M. and Takeuchi served as the interviewers and observers.

(1)-2 Typical Developmet (TD) Group

Among the nine participants in the control group, seven of them had children in elementary school and two of them had children in junior high school. The interviews for the TD group were conducted by Araki at each participant's residence.

Table 1: Characteristics of the Participants

ASD Group

Case	Name of Disorder (At the Age of Making Period of Diagnosis)	Grade	Type of ClassSchool Attendeding	Siblings	Area of Residence
1	High-Functioning Autism (3:8)	Elem 1	Ordinary Class	None	City A
2	Asperger's Syndrome (3:7)	Elem 3	Ordinary Class	Younger Brother	City A → E City
3	Autism Spectrum (2:1)	Elem 4	Special Support Class	None	City A
4	Autism, Mental Retardation (3:0)	Elem 4	Special Support School	None	City B
5	Pervasive Developmental Disorder (2:6)	Elem 4	Ordinary Class	None	City B
6	Asperger's Syndrome (3:3)	Elem 4	Ordinary Class	Younger Sister	City C → City A
7	High-Functioning Autism (3:1)	Elem 6	Ordinary Class	Younger Brother	City A
8	Pervasive Developmental Disorder (3:2) → Asperger's Syndrome (6:4)	Elem 6	Ordinary Class	None	City A → City D
9	Asperger's Syndrome (4:0) → High Functioning Autism (Elem 1)	Junior High 1	Special Support Class	Younger Brother	City A
10	Autism Spectrum (5:8)	Junior High 1	Ordinary Class	Two2 Younger Sisters	City A
11	Asperger's Syndrome (4:6)	Junior High 2	Ordinary Class	Two2 Younger Brothers	City A
12	Autism (Elem 1)	Junior High 1	Special Support Class	Younger Brother	City D

TD Group

Case	Grade	Siblings
A	Elem 2	1 Younger Sister
B	Elem 2	None
C	Elem 3	1 Younger Brother
		1 Younger Sister
D	Elem 4	1 Younger Brother
		1 Younger Sister
E	Elem 4	1 Younger Sister
F	Elem 6	1 Younger Brother
		1 Younger Sister
G	Elem 6	1 Younger Brother
		1 Younger Sister
H	Junior High 1	Two2 Younger Sisters

Note: With the exception of case C, all of the mothers were employed

(2) Procedure

The survey of parents who had children with ASD consisted of two parts: 1) Life-Line Interview Method interviews and 2) semi-structured interviews. Prior to the interview, documents including a letter requesting participation in the survey, the semi-structured interview sheet, and a questionnaire about the participant's children were sent to the participants' residences, and the completed forms were collected on the day of the interview. The questionnaire contained five items: 1) the child's gender, 2) the child's affiliation (school), 3) the child's current age, 4) the name of the child's disorder, and 5) the child's current condition. The questionnaire for the TD group contained questions on birth date, current age, gender, siblings, affiliation (school) and a blank space to describe any worries concerning child rearing.

Prior to the interview, we explained about the survey and privacy protection to the participants and obtained their permission to record the interviews to avoid any data being lost or unclear. Consent forms were obtained from all of the participants.

(2)-1 LIM interviews

The procedures for the LIM (Life-Line Interview Method) interviews were in accordance with the procedures described in Schroot's research (2004). In implementing the LIM, an A4-sized sheet of paper for the life-line framework was prepared. The framework was constructed with two horizontal lines (286 mm) and three vertical lines (174mm) which touched the horizontal lines at the 0mm, 174mm and 296mm points, with the vertical line on the far right edge being indicated with a dotted line (see Figure 1).

In the interviews, we explained to the participant that the horizontal line and vertical line represented the chronological order of his/her life from right to left and degree of happiness (bottom: unhappy, top: happy) respectively, and that the center line (the vertical line at the 174mm point) and the center vertical line indicated the present time and the central point of the left vertical line indicated

the time of his/her birth respectively. Next, the participant was instructed to draw his/her own “life-line” from birth until the present time. After the participant finished this task, he/she was asked to write his/her age at all of the peaks (top) and valleys (bottom) recorded on the line, and then to talk about the events that had happened at each of these points in time. He/She was asked to imagine it was his/her own life and fill in the ages, and was asked to write his/her future life-line on the paper from the center vertical line to the right vertical line as from the present until the end of his/hert life (the 296mm point on the vertical line). Lastly, He/She was asked to write his/her age on the peaks and valleys of the future line and to talk about the events that were likely to occur at these points in time. The LIM interviews lasted between twenty minutes and one hour.

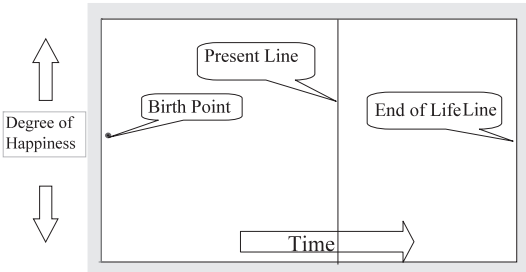


Figure 1: Life-Line Framework

(2)-2 Semi-Structured Interviews

A revised version of the semi-structured interview method was used. We reviewed the results of the pilot study and revised parts of the interview procedure and topics covered. Specifically, we conducted the interviews in chronological order focusing on events after the child was born, including five major topics: 1) the periods of “awareness,” “indication,” “diagnosis,” and “treatment,” 2) the treatment program, 3) the current situation, 4) the future, and 5) current needs (what the children need in terms of medical treatment, rehabilitation, education and society). In order for the participants to recall past events easily, the inter-views focused on life events in two periods: 1) events from child’s birth until

he/she started attending school, and 2) events from when he/she entered school until the present. We also asked parents who had children in junior high school about events “after graduating from elementary school and entering junior high school.”

When there was an overlap with the life-line we avoided asking the same question again during the semi-structured interview. Upon receiving a response we proceeded in a flexible manner based on the progress of the interview and took precautions not to place a psychological burden on the participants. At the end of the interview we asked the participants whether there was anything they had forgotten to say during the interview or anything they would like to add.

Table 2: Content of the Semi-Structured Interviews

Major Items	Sub-Items
① Babyhood	*Feelings when the child was born *Difficulties in raising the child in babyhood
② Awareness, Indication, Diagnosis, Treatment	* Period and matters of awareness * Period and matters of indication * Period and matters of diagnosis * Period and matters treatment (regarding the content, detailed interviews were conducted in ②).
③ Treatment	* Early treatment programs and their evaluation * Nursery School/Kindergarten programs and their evaluation * School programs and their evaluation (when currently enrolled in junior high school)
④ Present	*school selection * support received * Current difficulties ((1) Education (2) Friendships (3) Daily Life (4) Others)
⑤ Future	* Future desire * What do you hope for the future?
⑥ Comprehensive Questions	* What are your needs concerning medical treatment? * What are your needs concerning early intervention program? * What are your needs concerning educational program? * What are your needs concerning community and government?

3. Results and Analysis

1) Results of the Life-Line Method interviews conducted on Parents who have Children with ASD

The life-lines produced by the 12 participants showed three major patterns, based on an analysis focusing on the period of the child’s birth, the period of diagnosis of the child’s disorder, the period of the child’s early treatment, the periods during which the child attended nursery school/kindergarten and elementary school, the present time, and the future. We will discuss the characteristics of each pattern below.

Table 3: Life-Line Patterns

Pattern	Case Number	Maters
1	3,5,7,9,11	The child’s birth is at the peak of the line, and the line drops to the bottom at the time of the child’s diagnosis. After diagnosis, the line rises to the present (figure 3).
2	6,8,10	Marriage is at the peak of the line, and the line drops after the child’s birth. The line becomes flat after the parents are relieved to learn when they were not to blame for the child’s disorder. The line drops when the child is on the admittance to junior high school due to impending upcoming difficulties. The line drops because of from anxietyies related to the issues involving high school and as well as employment (figure 4).
3	1,2,4,12	The child’s birth is at the peak of the line, and the line it drops after the child’s developmental problems are indicated. The line rises and becomes flat after the child begins receiving treatment and rehabilitation service. The line also rises from the present into the future as well (figure 5).

Nine of the participants drew life-lines with a similar shape; the child’s birth was the high point of their life in terms of the degree of happiness, the line then dropped to the bottom of the degree of happiness scale at the time of the child’s diagnosis before rising to the center line marking the present time (Pattern 1).

Other than Case 3 and 9, these cases were characterized by the life-line not rising above 0 where it intersected present line. Nor did these life-lines rise above 0 from the present to the future. Depression in the line could have been due to anxieties about issues concerning the child's adolescence, admission to university, and employment. In Case 7, the line did not rise due to the participant's concern about being disappointed if he/she expected too much.

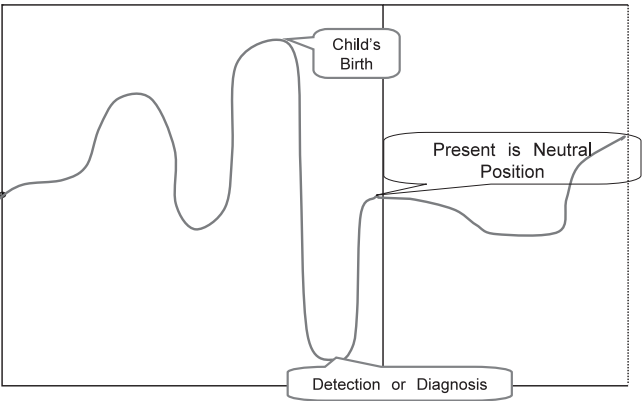


Figure 3 : Pattern 1

In Pattern 2, marriage was drawn as the highest point, and the line dropped to its lowest point when the participant was dealing with difficulties related to child-rearing after the child's birth, e.g., constant crying and hyperactivity. From the time of the child's diagnosis, a flat line is observed where the parents stated they were not to blame for the child's disorder. It is important to note that at this time they had anxiety about the child's future. Upon the child's admission to junior high school the line drops to the bottom with the statement that they were confronting other problems. From the present to the future, the line remains at the bottom with the parents expressing anxieties about their child's admission to high school and subsequent employment (Case 10).

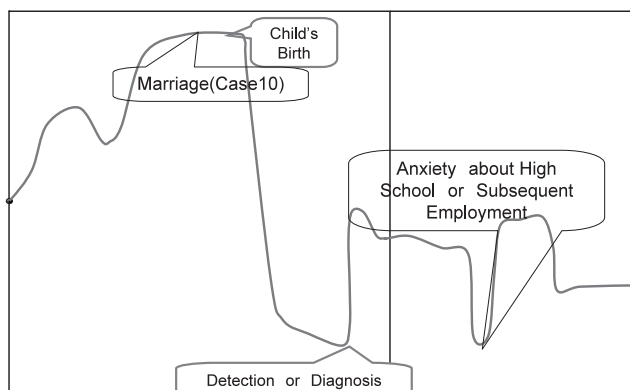


Figure 4 : Pattern 2

In Pattern 3, the child's birth is at the top, and the line dropped to the bottom with the statement that the child's developmental problems were being pointed out by others. The line rises with the commencement of treatment(top). In Case 4 pattern, the line does not drop even at the point where a diagnosis was confirmed after the commencement of treatment. Receiving treatment renders the line stable and the line rises with hope for the future.

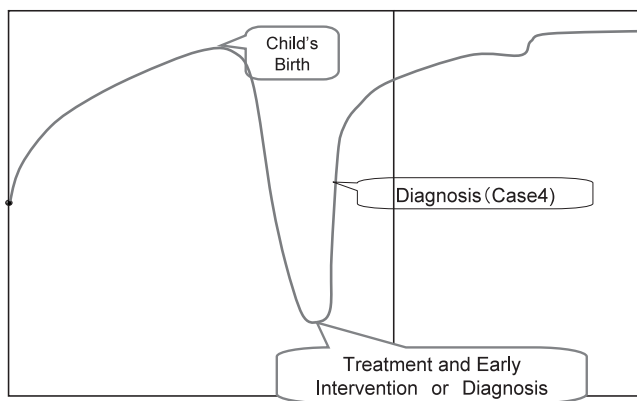


Figure 5 : Pattern 3

The following characteristics can also be noted on the basis of an analysis of the life-line. First, in most cases, the time of marriage or child birth was at the top of the degree of happiness scale and the point in time when the child's disorder was diagnosed, indicated, or the parents became aware of it was at the bottom. Second, in some cases the line dropped due to the diagnosis (Case 6), but in other cases the process leading up to the diagnosis is at the bottom and the line is flat after the diagnosis has been made (Case 10). Third, there was a tendency for the line to gradually rise after the child's diagnosis, but the subsequent trajectory cannot be generalized, so it may be necessary to further examine its correlation with the provision of support services. In particular, in most cases the line dropped during the transition period, i.e. entering elementary and junior high school, as well as when the child moved up to a higher grade, and whether sufficient support services were provided is also a critical issue. Fourth, regarding the future, in some cases the participant had specific images of the child's future, in other cases they were focused on the present and could not imagine the future, and there are also cases in which the parent simply had a positive image of the future no matter what the child's condition might turn out to be. In this study Pattern 1 was the most common, but it is necessary for us to examine the exceptions in order to provide support to parents. In addition, in some cases the parents had children over twelve years of age, which is along period of time of which to be aware. It is therefore likely that their LIM life-line was simplified. In the studies conducted in Vietnam and China, which were reported at the seminar in Nanjing November 2012, all of the participants had children at the point of starting school, and their life-lines from birth to the present formed zigzags with repeated lows and highs. One explanation for these results is that the participants were truly in the midst of a difficult situation and had predicted a worse situation in the future. In the current study, on the other hand, in case 10 the participant's child was a junior high school student, and the participant stated that the situation was also difficult when the child was small but the present was the most difficult time. The line shape could thus vary with the age of

the child.

In this study, the number of participants is still limited, and it is therefore necessary to increase the number of participants in order to generalize the difficulties that parents who have children with ASD go through.

2) Comparison of the parents who have children with ASD and the control group

During the analysis of the life-lines of the parents who had children with ASD and the control group, life events were divided into past (from marriage/childbirth until the present) and future, and the highs and lows of each group were focused on (Tables 4, 5). The events stated at the highs and lows were analyzed and the rising and falling of the line at each point in time were marked. The results were as follows. 1) The negative events stated by the parents who had children with ASD were related to problems with their children. In contrast, in the control group half of the negative events were related to problems related to the parents' children and the other half were related to other personal and family problems. 2) Among the parents who had children with ASD, the lines gradually rose to the top with statements such as that it would be disappointing to expect too much but they want to view the future positively, or that they felt things were getting better. In only three cases did the line drop to the bottom in the future. In the control group, the lines dropped to the bottom with statements such as that the child would probably cause problems and that some problems would probably occur. 3) While the parents who had children with ASD placed the child's birth and their marriage at the top, in the control group the child's birth was placed at the bottom with statements about difficulties in raising a child and working at the same time (two cases), and discord with other family members (one case). 4) Eleven parents who had children with ASD placed the diagnosis of the child's disorder at the bottom of their lines. One parent placed the diagnosis at the top, but their line then also dropped to the bottom. 5) In one case in the control group factors related to the

child were noted at the bottom of the line.

Overall, almost all of the events stated by the parents who had children with ASD involved their children, and this was clearly not the case in the control group.

Table 4: Types of Life-Lines after the Child’s Birth (ASD)

	Past	Future**
“Highs”	Birth of the child (11*) Child starts elementary school (2) Child starts junior high school (2) Line rises from the “low” due to starting treatment (2) Growth perceived at elementary school (1) Diagnosis (1)	Expecting too much will cause disappointment, desire to depict the future in an “upward” manner. Although many things will likely happen,our happiness will increase (3) Enter society (2) Gain employment and settle down by around age twenty-five(2) Settle down after becoming independent (1)
	Marriage (3*) Birth of a second child (2) Residence overseas (1)	
“Lows”	Indication of a disorder(1) Diagnosis (10) Difficulties in childrearing (1) Second diagnosis (1) Child becomes a junior high school student (1) Path to advancement to junior high school, high school, university, etc. (5) Adolescence, etc. (2) Period of compulsory education (1) Social support, etc. (1)	Path to advancement to junior high school, high school, and university, etc. (5) Adolescence, etc. (2) Period of compulsory education (1) Social support, etc. (1)
	Current worries (1) Problems with second child (1)	May encounter trouble in one’s own life (1)

Note: The numbers in parenthesis in the table are a total of all such responses.
 *In this table “birth of the child” includes responses of “marriage and giving birth” (three cases)
 ** Regarding the future,there are cases where the line rises steadily from the present, and cases where the reason for the rise is not stated and there are few events.

Table 5: Types of Life-Lines after the Child's Birth (Control Group)

	Past	Future
~Highs~	Birth of the child (5) → From marriage until the birth of the second child, including the time from the birth of the first child to the present	Child become an adult (2) Child becomes independent (1) Get through a stage in childrearing (2) Birth of grandchildren (2) Child reaches the higher grades (1) Child gets married (2) Third child enters elementary school (1)
	Birth of a third child (1) Child rearing settled down (1)	
	Recovered from the shock (1)	Husband reaches mandatory retirement age (1)
	Marriage (2), Everything up to now (1) Changed way of thinking (1) Daily living settled down (1)	Mandatory retirement (2) Live a free life (2) Something good happens (1)
~Lows~	Birth of a child (4*) Birth of a third child → Combining child rearing and work (2) Large shock from a death in the family (1) Marriage (1) Remarriage**(1) Conflict in the family(1) Poor mental health (1)	Child's Adolescence (2) There may be something wrong with the child (1) It seems like the child will cause a problem (1) Child's entrance exams (1) Child leaves home (1) Death of both parents (3) Taking care of a parent (2) Husband's death (2) Difficulties in daily life related to events such as the child taking entrance exams (1) Menopause (2) Poor physical health (1) Old age (1)

* "Birth of child" includes responses of "marriage and giving birth" (2 cases)

** "Remarriage" is at a low after which the line heads toward the top.

3) Needs Analysis based on the Semi-Structured Interview Method

After the LIM interviews, we conducted interviews using the semi-structured method. We conducted the interviews with a structured document (see, Table 3). We analyzed a portion of the content.

(1) Characteristics of each Age Period

(1)-1 Babyhood during the first half of the neonatal stage in which a child usually sleeps for long periods and there are no noticeable problems, in many cases of children with ASD the parents recalled some difficulties in taking care of their children, e.g., the child was always crying and would not stop, showed no interest in other people, or moved around restlessly. In the second half of the neonatal period, the parents' concern about their child's behaviors increased, e.g., the child never said 'bye-bye', the child was so shy that he/she made no eye contact with others, the child was awake all the time from the age of five months and had to be held all day even though he/she had slept normally in the past, or the child showed no reaction when his/her name was called. However, no physical impairments were detected in medical examinations. Therefore, the parents could not tell whether there was a problem with their child or the child's behavior was part of a normal developmental phase. They tried to overcome these difficulties.

(1)-2 From Awareness to Diagnosis

Anxieties about the children grew after they reached the age of one. If it was their first time raising a child, however, the parents did not recognize the underlying problems, and even if they sought advice from public health nurses they were sometimes told that they were worrying too much (Cases 2, 6, 10). As a result of this they were convinced that their child was normal until their condition worsened, which delayed his/her diagnosis. In many cases, the parents

started to become aware of their child's problems as raising him/her became more difficult. Therefore, there is a strong need for access to pediatric experts.

(1)-3 From Indication of a Disorder to its Diagnosis

In many cases, the hardest period for the parents was the one in which they are aware that problems had been observed but no diagnosis had yet been confirmed. In some cases, even if the parents received consultation, they were provided with neither specific instructions nor solutions. If children were diagnosed shortly after parents received indications of their disorder they were able to receive treatment that lead to an enhancement of their development as well as their abilities. Upon receiving the diagnosis of their child's disorder, parents were relieved even though they then had to confront and solve other problems. In some cases the parents did research on their own and become emotionally ready to accept the diagnosis as something they expected. In other cases, the parents were very shocked. This is not just the case with ASD; parents whose school-aged children are diagnosed with a learning disability (LD) are also shocked.

(1)-4 Treatment program

The progression from receiving indications of a disorder to diagnosis and treatment differed case by case. Treatment programs and parents' satisfaction with treatment programs also differed. Parents evaluated their child's treatment program based on whether it was enjoyable for both them and their child, whether the site was comfortable, and whether they were able to continue to receive it. In some cases, the parents wanted a place where they could share their problems, not just a place that was comfortable for their child. When and where treatment can be accessed is a crucial factor in raising a disabled child. Parents were immediately relieved after receiving essential advice and responses to their questions and anxieties. The role of the treatment facility is therefore indispensable. According to Asuka Maeda's report (2010) on the progression from aware-

ness of a disorder to receiving indications, diagnosis and treatment entitled “A Research Study for the Support of Parents of Children with Autism Spectrum Disorder? A Comparison of Children with ASD with Mentally Retarded Children,” there is a greater time delay between the awareness, discovery/diagnosis and intervention stages in the case of children with ASD than in the case of mentally retarded children. This report raised the question of whether this delay may cause the psychological anxiety and conflict involving children with ASD.

After the disorder was diagnosed, rather than remaining shocked most of the parents who had children with ASD accepted the diagnosis, thought about a method to cure ASD, and felt relieved that the way they had raised their child had not caused his/her ASD. Araki also argues that the parents’ awareness (awareness-->indication) should be confirmed as early as possible to prevent a time delay that can cause an increase in their anxiety, and that a system which immediately refers parents to specialized consultation with pediatric experts (indication-->diagnosis) would lead to earlier diagnoses.

(1)-5 School Attendance

Prior to their child starting school, the parents in the study considered which school would be best. This involved looking for the place that would be most suited to their child’s ability, and they paid frequent visits to schools from the time their child was in his/her second or third year of kindergarten. The type of support provided was often the key point in choosing the school. It was important to have someone who supervised the parents’ efforts and listened to their problems (4 cases). This key person was usually a spouse or a specialist at a treatment center. In elementary schools, there should be a key person. Proximity was also important in choosing the school to attend. In one case, the parents stated they did not want their children to go to an elementary school outside the local area, and their children also shared this preference (Case 9). In another case, they stated that the medical examiner explained that attending an ordinary class would be hard for their child but they did not want their child to enter a special class (Case 10).

(1)-6 After Enrollment in School

Upon their children entering school, the parents informed the school of their problems and requested special accommodation so that their school life would go smoothly. Currently, they are content with how the schools are handling the situation. They have, however, witnessed difficulties related to children attending school. The parents are reluctant to make or increase demands on the teachers. The interviews made it clear that the parents appreciated the fact that the teachers were providing assistance to their children. On the other hand, however, they also wished that the teachers would try harder. Issues related to school attendance exist among all children, not just children with developmental disorders. Therefore, the school-based issues for the children with ASD have to be given greater consideration.

(2) Analysis of Present Circumstances

In analyzing the data we divided the children into three categories by age: mid-elementary school age, late-elementary school age, and junior high school age.

(2)-1 Middle-Elementary School Age (3rd and 4th Grades)

During third and fourth grade, children start to learn abstract concepts, which require imagination and the application of skills based on basic literacy. Children with ASD often display difficulties in mathematics, written compositions, and other open questions. This problem has to be addressed through special consideration, e.g., teaching with concrete examples, in order for them to understand all of the relevant concepts without falling behind.

The school must also intervene in the relationships between children with ASD and their classmates, especially during recess. Problems sometimes occur due to misunderstandings between the children with ASD and their classmates. In order to avoid this kind of problem, this issue has to be addressed through special consideration, e.g., provision of information to the child's classmates about how

to communicate with children with ASD and interpersonal skills training for the children with ASD in group settings. Some problems such as the unstable temperament and unbalanced diet observed in children with ASD can be solved before the children go to school. For example, parents often try hard to encourage children with ASD to correct an unbalanced diet or to get into the water in a pool (most autistic children don't like to be in water), before they start school. The needs of children with ASD are in these areas. In school-based settings they can thus improve their social skills as well as enhance developmental abilities, overcoming the innate problems of ASD.

(2)-2 Late-Elementary School Age (5th and 6th Grades)

During the later years of elementary school, children with ASD display difficulties in understanding complicated concepts and expressing their ideas constructively. Teachers should help them understand abstract concepts and express their own ideas in multiple steps in a way that will allow their classmates to understand them easily. All of the children whose parents participated in this study had friends to play with, and they were neither being isolated nor bullied at school. Establishing intimate friendships will presumably become an issue in adolescence when friendships are based on trust and mutual understanding.

In daily life, broadening interests is an issue to be addressed in addition to the enhancement of the child's overall capabilities. Initially, the activities that they are interested in and good at should be facilitated and converted into other activities. The relationship between parents and children changes as the children enter adolescence. Interpersonal relationships advance to the next stage in which not only children with ASD but also their parents face more difficulties.

(2)-3 Junior High School Age

In junior high school, children with ASD spend most of their time in classes and club activities. The level of academic performance required in junior high school is significantly higher than during the elementary school period. Al-

though the school's principal and the children's home room teachers are informed of their disorder, most of the parents have given up on receiving special support from teachers because at this point their child's future after graduation is coming within sight and they often worry so much that they do not know what to do about the situation at school.

In junior high school, teachers take turns teaching different subjects at a higher academic level than in elementary school, which is a major issue for children with ASD. It is harder to identify the children's weaknesses related to their disorder and to respond immediately to problems they have in junior high school than it is in elementary school. It is as important for children with ASD to learn to establish an intimate relationship with peers of the same age. Developing interpersonal skills is a major requirement related to the transition to adulthood. In daily life, new problems involving adolescence sometimes arise. It is necessary to teach children with ASD about the characteristics of adolescence, e.g., physical changes, gender distinction, menstruation, etc.

(2)-4 About needs after the children with ASD start school

The needs of children with ASD become individualized as they get older. Although the specific situation is different in each family, all of the parents reported using a process of trial and error. In addition, the needs of parents who have children with ASD in school settings are varied. Considering the children's perspective, the response to their needs should be careful and concrete. The needs of children with ASD are not negligible, especially in regard to academic skills. Even if the family understands the child's problems, they recognize the limit of what they can do for their children, and his/her problems become severe. As the academic level of the curriculum gets higher, the children with ASD gradually fall behind in their classes, especially in the understanding of abstract concepts. Therefore, the needs of the parents can be understood as differing according to the three age groups mentioned above: the mid elementary school age, the late elementary school age, and the junior high school age.

One of the biggest worries of the parents of children with ASD is their friendships with peers. Maeda (June 2010) reported that difficulty in making friends is common among children with ASD, and special support must be provided. In this study, however, the participants reported that friendship was not a major problem and that their children established friendships in their own way. One reason may be that the participants' children attend treatment sessions once a month at Ritsumeikan University in which they are helped to acquire interpersonal skills and given good opportunities to bond with other children with ASD. This provides evidence that children with ASD are capable of seeking and establishing friendships. In case 10, however, although the parents thought that there were no problems with friendships, the child stated that he had no friends. It is possible that the major issues involving friendship arise beginning in adolescence and subsequently cause other difficulties in relationships with other people. In other cases, difficulties related to friendships were resolved with family assistance (Cases 2, 4), and relationships were formed by the teacher intervening and having the child play a "big brother" role with children in lower grades (Case 3).

One of the problems children with ASD encounter in junior high school is higher academic requirements, and another is participation in club activities and their relationships with peers. During the junior high school period, the parents' LIM life-lines dropped to their lowest point. Children attending special support schools, however, receive assistance in getting into a high school, and therefore in the case of this family the problem was not as severe (Case 12).

Four parents who had children with ASD in junior high school and the later-grades of elementary school participated in this study and they are facing problems similar to those indicated above.

During the middle elementary school years, the condition of the child was usually stable. The parents who participated in the study for the situations that would arise and responded to new problems immediately.

In the analysis conducted for this study we categorized the participants' children

by school age (middle elementary school age, late elementary school age, and junior high school age). We were able to clarify the differences between the parents' needs during the relatively stable period of the child's elementary school years, the period of the transition to junior high school, and the challenging period of the child's junior high school years. The participants' LIM life-lines also dropped to the bottom of the happiness scale from the time the children entered elementary school to the time they entered high school. Arai points out the necessity of a continuous support service system during the transition period from elementary school to junior high school. It is necessary for parents to have access to experts who can then give appropriate advice on their children's school affairs as well as supply mental health care when their experience increased anxiety.

(3) Future Needs

(3)-1 Desires for the Future

The parents' desires for their child's future were complete independence, independence with support, and environmental adaptation to achieve independence. The child doing what he/she liked as a profession was a major desire as well. The parents who had a child in junior high school expressed not only a desire for their child's independence but also the realistic, earnest hope that he/she would go on to attend high school and university.

(3)-2 The predicted Upcoming Desires

The expected future desires were that the child will be loved by others, be confident, find a favorite thing to do, and someday his/her disorder will be cured. In some cases, the parents who had children in elementary school stated they were too busy to imagine the future. These parents will have to consider solutions to the problems their children will face when they start junior high school.

(4)About the Comprehensive Questions

(4)-1 Needs related to Medical Treatment and Rehabilitation

The parents stated that psychiatrists for adults should be more accessible, that they wanted someone who listens to them, that their children should have assistance in academic affairs, and that the severity of autistic symptoms should be reduced through medical treatment and rehabilitation. They wished they had had support before the diagnosis and places available for them to talk about their children informally.

(4)-2 Needs related to Education and Society

Experts who understand ASD and can provide appropriate advice were what was most needed. In addition, financial support and assistance regarding the academic curriculum were also requested by the parents. In other words, the acknowledgement and understanding of Autism must be implemented in society.

In Arai's report (June 2006), the section on rehabilitation and education indicates that more expert physicians who can explain to parents about how to raise children with ASD, including providing them with general knowledge on autism, are required along with medical treatment. In rehabilitation, support to encourage the parents to accept and understand the child was also an issue, while the parents requested support suited to the child's development and disorder. Building a system that links medical treatment, rehabilitation and education and provides support from the standpoint of the parents and the child will thus likely become an issue to be addressed going forward.

(4)-3 Future Needs

It is perfectly natural that parents want their children to be independent. In the case of ASD, however, without public understanding of autism this desire cannot be realized. Most parents strongly want their children to find something they like to do and make it their livelihood. Parents therefore encourage their

children to do what they are capable of doing and impose multiple tasks on them. Initially, it could be an excessive burden for the children, but without knowing whether it will be possible for their child to develop professional skills and what the future situation will be like, the parents are just trying hard to do what they can to break out of a situation in which they are anxious about their child's future.

4. Discussion

1) The Feelings of the Parents

- a. The parents have wishes for the future and confront reality.
- b. They make necessary efforts in order to guarantee the child's current situation.
- c. On the other hand, they are concerned that their child's future choices may be limited (they worry about whether their child will be able to grow up to be what he/she wants to be).

2) Dealing with the Educational Ladder

In the case of Japan, the early detection and early intervention systems for children with developmental disorders have been progressing. According to the "Act on Support for Persons with Developmental Disabilities," however, there are still many issues involving the necessary support and the level of school education. In junior high school, the teachers and staff do not have much contact with parents and do not provide as much information as in elementary school. Since junior high school education is the final stage of compulsory education, frequent consultation concerning the child's condition, skills, and wishes is required in order to make the most appropriate decision concerning his/her career on the graduation of compulsory education.

3) From “Awareness” to Indication, Treatment and Diagnosis

After the birth of the child, the sequence of awareness of the disorder → indications from others → treatment → diagnosis described in Arai (2010) was also observed in this study. There were, however, cases in which the parents did not receive treatment services. The most significant responses from the parents were as follows:

- a. The parents visited a facility at an early stage for a diagnosis. They had received indications of the child’s disorder and advice from others.
- b. Although the parents recognized their child’s odd behavior from early on, they had difficulty accepting it.
- b. The parents were relieved that their child’s odd behaviors were explained by the diagnosis.
- c. The parents, not knowing what to do, tried to convince themselves that the way they raised their child was not to blame for his/her disorder.

4) What was Made Clear ?The Period from Elementary School to Junior High School

- a. The elementary school years were generally a stable period, and major problems did not arise.
- b. Cooperation as well as support from the school was able to be obtained.
- b. The children’s various individual needs could not fully be met. This problem was caused by the limited staff and teachers at schools.
- c. The academic content of what was taught to the children was mostly related to the standard junior high school and high school curriculum, and further adaptation to the child’s abilities is still necessary.
- d. There were no cases in which children were isolated from classmates, and they spent time with their friends outside of school as well.

- e. Due to the consideration of their parents, the children have no problems in daily life.

(4)-1 What was Made Clear ? Part 1: The Elementary School Period

- a. During the elementary school period, cooperation as well as support from the school was able to be obtained, and as a result not many problems arose.
- b. The children generally avoided difficulties that might become problematic in their school life.
- c. When the children moved up into the higher grades (particularly 6th grade, the last year of elementary school), their parents' anxieties about their future started to grow. Worries about changing circumstances such as "every-day life will probably be different," "relationships with classmates will probably change," and "it may be difficult to obtain cooperation again" increased the parents' anxieties.

(4)-2 What was Made Clear ? Part 2: The Junior High School Period

- a. In junior high school, it was harder to obtain cooperation from teachers and to maintain relationships with other students. In junior high school, unlike the system in elementary school in which a single teacher teaches all five subjects to the same class, five to eight teachers take turns teaching different subjects, which discouraged parents from consulting with teachers about their child's issues.
- b. In addition to following the academic curriculum, some of the children participated in club activities. In some cases, their relationships with other students in school clubs generated problems.
- c. Parents became more anxious about their child's career path after graduation from junior high school.
- d. Upon the decision to continue education at a high school, parents became concerned with increasing their child's academic abilities.
- e. Problems related to adolescence were more likely to appear.

5) Life long Support. The condition of children with ASD may improve with appropriate support, but continuous, life long support is required.

- a. From the time the parents become aware of the disorder until the child grows up to be an adult in society, it is necessary to ensure continuous support. What kind of support is to be provided has to be considered.
- b. Individualized support is required during transition periods, e.g., close inspection of the child's reaction to a new environment and relationships with other students.

6) Acceptance of the Disorder

In one of the interviews, a mother stated that she had not accepted her child's disorder. Parents also emphasized medical progress, expressing a belief that their child's disorder could be completely cured or that in the future there would be medicine to attenuate its severity. Accepting the disorder is probably hardest for parents. At some points they observe significant improvement in their child, but at other points he/she shows no improvement at all for a long time. They thus have to confront their child's present condition caused by his/her disorder and choose the support they need. Therefore, concerning the future the parents thought they would be disappointed if they expected too much but still had hope in many respects. The parents who had three children stated they had considered how to solve the problems. Upon the child's enrollment in junior high school the family's problems became more complicated. The existing support system was also called into question. Just one solution to each problem does not solve all of the problems involving children with ASD. Accepting the disorder is not just understanding that the child is disabled. The parents must evaluate the child's difficulties in daily life and find out what has to be done in order for their child to live in a way suited to him/her. Takako Sashika (2007) points out that the parents of children with

this kind of disorder experience a crisis situation upon the acceptance of the disorder not only once but repeatedly as the child encounters developmental issues at each stage of his/her development. The parents' responses are probably a manifestation of this sentiment.

7) Significance of the Interviews

Some aspects of the needs of parents who have children with ASD have been identified on the basis of the responses obtained in the semi-structured interviews conducted as part of this study.

Some participants in this study reaffirmed their acceptance of their child's disorder and also reported that they have had opportunities to see how children should be raised. They re-accessed their childrearing methods in the process of interview. Some parents (case 10) stated that they were delighted to find out they were being listened to.

The parents' mental states at the events noted in the life-line and the actual events would be different. Certain similarities among the participants, however, were observed throughout their lives from their child's neonatal period to his/her school years. This indicates that common needs of parents who have children with ASD were successfully identified in this study.

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