Research on the Needs of Children with Autism Spectrum Disorder and Their Families in Japan:
A Comparison with Children with Mental Retardation

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1. Introduction

Autism Spectrum Disorder (ASD) is characterized by impaired social interaction and communication, and by restricted and repetitive behavior (Wing, L and Gould, J, 1979). Therefore, it has been reported that the parents of children with ASD have various difficulties regarding the acceptance and recognition of their child's disorder by the people around them due to reasons such as its not being readily visible and its diagnosis being difficult (Natsubori, 2001; Song, Ito, Watanabe, 2004).

In a report by Natsubori (2001), in which a comparative investigation was conducted into the age at which children with autism and Down's Syndrome had their symptoms "suspected/noticed" and their condition "diagnosed," there was no difference found between the ages at which "suspicion/noticing" and "diagnosis" for children with Down's Syndrome occurred; within 6 months of birth a disorder was suspected, leading to an immediate diagnosis. In contrast, for children with autism, a period of up to 1 year and 4 months was needed

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between “suspicion/noticing” and “diagnosis.” Also, in a report by Minesaki and Ito (2006), there was no significant difference found regarding the age at which “suspicion/noticing” occurred in children with high-functioning autism and those with mental retardation, but it was clear that for children with high-functioning autism the timing of their “diagnosis” was significantly later than that for mentally retarded children. In addition, there are also reports that in contrast to “suspicion/noticing” of children with autism at the age of 1 and a half to less than 2 years of age, “notification” peaked between the ages of 3 years and 3 years 5 months old (Nagai, Hayashi, 2004). Compared to other disabled children, a time lag between when the parents notice their child’s disorder and its diagnosis is a characteristic problem for children with ASD.

For the parents of children with ASD, it is assumed that they experience a vague anxiety during the period of time between first suspecting their child has a disorder and a diagnosis being made, and this period is very difficult for them. Ishikawa (1999) states that even if a parent has feelings of resistance toward the diagnosis, participation in treatment and education programs transforms this “vague anxiety” into more proactive feelings, and since this also leads to the parents’ emotional stability, a follow-up system to treatment and education, etc. should be established. In addition, while detecting the child’s disability early and diagnosing it is important from the perspective of future support and the child’s prognosis, expanding support systems for parents and families who have vague anxieties because they suspect a disorder but no diagnosis has been established is also an important issue. For this reason as well, we must think about the way diagnosis, notification and support both before and after diagnosis should be handled, taking into account the time lag characteristic of the diagnosis of children with ASD.

In recent years attention has been focused on support for children with ASD, and numerous research studies and reports have been done on this topic, but the reality is that little research has been done on either the worries and needs of parents generated by the aforementioned time lag characteristic of the diagnosis of ASD or the relationship between these worries and needs and parents' experience of treatment and education. Furthermore, parents' anxieties do not disappear just because a diagnosis or notification has been made; they encounter various difficulties after their child's diagnosis as well. It has also been reported that the process of the parents accepting the disorder is experienced repeatedly, not just once, when new problems occur at each of their children's developmental stages (Sashika, Hirayama, 2002). In response to the various problems which occur due to the characteristics of children with ASD, comprehensive clarification is required as to what parents see as a problem both before and after the notification and diagnosis and in the period that follows, as well as what type of support they desire.

2. Purpose

In previous research (Maeda, Arai, Inoue, Zhang, Araki, Araki, and Takeuchi, 2009), a pilot study was implemented targeting only children with ASD, and a comparative examination was performed regarding the current state of child rearing support and the needs of parents of children with ASD in their preschool-age and school-age years. This study builds on previous research, and, while revising the questionnaire items, increasing the number of participants, and performing a comparative analysis of children with ASD and other types of mental retardation (MR), clarifies the existing state of affairs concerning the support and needs characteristic of parents of children with ASD.

3. Method

3-1 Participants and Procedure

The questionnaire form was distributed to parents of children attending resource rooms, special needs classes, schools for special needs, institution/day care for preschool children with special needs, and parents' associations in Kyoto Prefecture, along with a return envelope addressed to the university laboratory. Collection was handled by either having the parents directly mail the reply envelope or having each organization collect all of the envelopes and mail them to the university laboratory. The survey period was from June to September 2009. Responses were received from 229 people (a response rate of 31.1%), and, after excluding incomplete replies, 209 (136 parents of[RC1] children with ASD and 73 parents of children with MR) were targeted for analysis. The characteristics of the children of the participants are listed in Table 1. Details of the disorders that the children with MR had are listed in Table 2.

Table 1. Characteristics of the Children of the Participants

N=209		ASD	MR
		136(65.0)	73(35.0)
Gender	Male	108(79.4)	42(57.5)
	Female	28(20.6)	31(42.5)
Preschool Age	Day nursery or Kindergarten	36(26.5)	6(8.2)
	Institution/Day Care for Preschool Children with Special Needs	18(13.2)	12(16.4)
	Home	1(0.7)	1(0.7)
	School for Special Needs	1(0.7)	0(0.0)
	Unclear	1(0.7)	0(0.0)
Elementary School	Regular Class	11(8.1)	1(1.4)
	Special Needs Class	14(10.3)	9(12.3)
	School for Special Needs	33(24.3)	22(30.1)
Junior High School	Regular Class	1(0.7)	0(0.0)
	Special Needs Class	4(2.9)	2(2.7)
	School for Special Needs	15(11.0)	20(27.4)
	Unclear	1(0.7)	0(0.0)

Note: Numerical values indicate the number of people, and the percentage of each group is indicated in parentheses.

Table 2. Details of the MR Group

	N	%
Mental Retardation	26	35.6
Down’s Syndrome	15	20.5
Chromosomal Disorder other than Down’s Syndrome	6	8.2
Cerebral Palsy	6	8.2
ADHD/LD	6	8.2
Epilepsy	5	6.8
Delayed Speech	4	5.5
Cerebral Deformity	3	4.1
Hearing Impairment	2	2.7
Total	73	100.0

3-2 Survey Contents

The questionnaire was composed of 8 fields and 48 items. The 8 fields were: 1) basic characteristics of the participant’s child, 2) family economic situation, 3) worries and anxieties in daily life, 4) state of child rearing, 5) desires for economic, lifestyle, and child rearing support, 6) thoughts about the child’s future, 7) detection and notification of the child’s disorder, and 8) early intervention and education for the child.

3-3 Analysis

By investigating whether there were any differences between the ASD group and the MR group in regards to the 48 items in the questionnaire, the particular feelings, support situation, and needs of parents of children with ASD were clarified. In addition, regarding the particular feelings, support situation, and needs of parents of children with ASD which were clarified, by investigating whether there were any differences in factors such as A) the child’s age, B) the child’s ability to communicate, C) the child’s level of hyperactivity, D) the existence of financial comfort, E) the period of “suspicion/noticing” of the disorder, F) the period when the disorder was detected, G) the period of intervention/education, H) the period of diagnosis, and I) the degree of satisfaction with intervention/education where necessary, we delved further into the problems and needs of children with ASD and their families and performed a detailed examination of these issues.

4. Results

4-1 Condition of the Participants

Initially, in order to clarify the conditions of the ASD group and the MR group, their degree of independence and ability to communicate, degree of difficulty in everyday life, and the presence or absence of hyperactivity were investigated. Regarding the degree of independence (Figure 1), the results showed that compared to the ASD group, the percentage of the MR group requiring assistance was significantly higher ($\chi^2(2)=13.19$, $p< .01$). Regarding the degree of communicative ability (Figure 3), the results showed that, compared to the ASD group, the percentage of the MR group who “cannot” communicate was significantly higher ($\chi^2(3)=8.07$, $p< .05$). In terms of the degree of difficulty in everyday life (Figure 3), too, a bias was seen in the number of people in each group ($\chi^2(3)=12.52$, $p< .01$). As a result of residual analysis, the percentage of the ASD group who “need to be helped in new situations and when they panic” was found to be significantly higher than that of the MR group, and, conversely, the percentage of the MR group who “need to be helped all the time” was found to be significantly higher than that of the ASD group. Regarding the presence of hyperactivity (Figure 4), the results showed that the percentage of the ASD group displaying hyperactivity was significantly greater than that of the MR group ($\chi^2(1)=6.17$, $p< .05$).

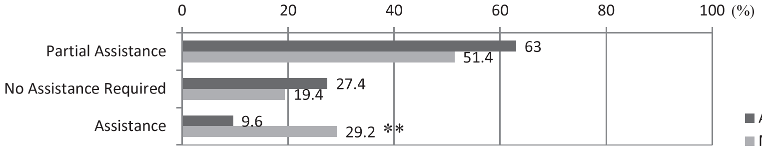

Figure 1: Degree of Independence

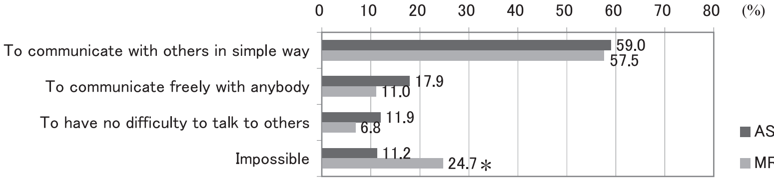

Figure 2: Degree of Communication Ability

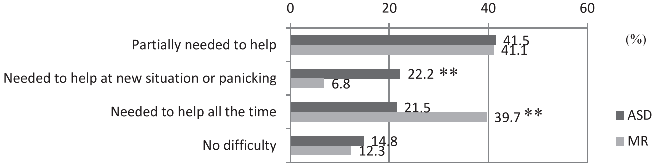

Figure 3: Degree of Difficulty in Everyday Life

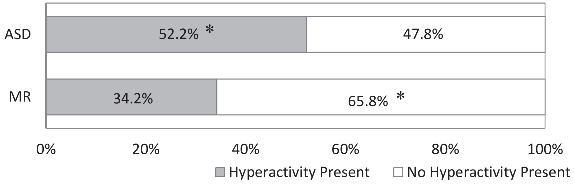

Figure 4: Degree of Hyperactivity

4-2 Parents' Daily Life and Child Rearing Circumstances

4-2-1 People to Consult with on Matters concerning Daily Life, Education, Medical Treatment and Welfare

Regarding who they could consult with about daily life, educational, medical and welfare matters, in both groups the majority of people responded "spouse," "teacher," and "another parent of a child with a disability." On the other hand, when both groups were compared, the results showed that a significantly greater number of parents in the children with ASD group listed "spouse" ($\chi^2(1)=4.38$, $p< .05$) and "teacher" ($\chi^2(1)=7.50$, $p< .01$. This shows that in more cases parents of children with ASD consulted facilities close at hand, such as the school or facility their child attends, regarding daily living, education and medical issues, in addition to their spouses, than in cases of children with MR (Figure 5).

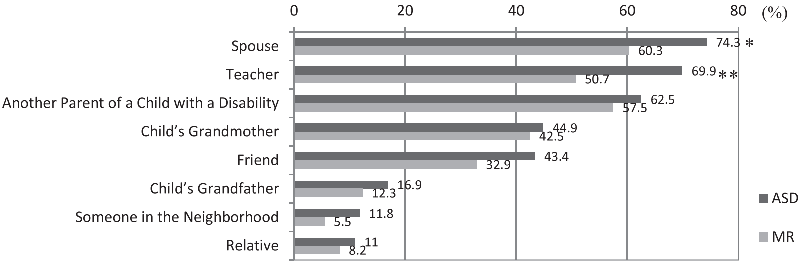

Figure5. People consulted on Matters concerning Daily Life, Education, Medical Treatment and Welfare

4-2-2 Current Worries and Anxieties

Regarding current worries and anxieties, we can see that a significantly greater number of parents in the MR group were worried or anxious about their “low income” than in the ASD group ($\chi^2(1)=9.86$, $p< .01$). One reason for this may be that, compared to the ASD group, a greater percentage of the MR group come from households with only a mother (the percentage of the ASD group not living with their father was 6.6%, and the percentage in the MR group was 17.8%, $\chi^2(1)=6.32$, $p< .05$). Also, we found that in both groups a large number of people were worried or anxious about a “lack of free time.” In the ASD group, since no significant correlation was seen between worries and anxieties over a “lack of free time” and the child’s age or the degree of the disorder, we can see that the parents had a great deal of worry or anxiety regardless of these underlying factors (Figure 6).

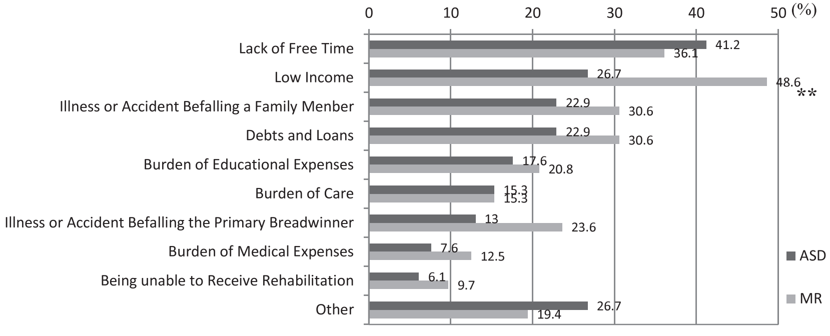

Figure 6. Current Worries and Anxieties

4-2-3 Worries and Anxieties about the Future

Regarding worries and anxieties about their child's future, we saw that, compared to the MR group, a significant number in the ASD group were worried or anxious about "their child securing employment" ($\chi^2(1)=12.6$, $p< .01$) and "their child getting married" ($\chi^2(1)=8.18$, $p< .01$) (Figure 7). Regarding the particulars of the disorder in the ASD group, there were far more cases of the children being hyperactive but having no difficulties concerning communication, as well as cases without mental lag, than in the MR group. Therefore, compared to the MR group, the parents of the children in the ASD group had strong hopes that their child would lead normal lives and get married, but they may also have strong worries and anxieties about these outcomes as well. The results of our detailed analysis of only the ASD group are shown in Figure 8. For "child getting married," parents with children less than 6 years old had a significant amount of worry and anxiety ($\chi^2(1)=6.72$, $p< .05$). On the other hand, compared with the parents of children under 6 years of age, we saw that a significant number of parents of children over 6 years of age had worries and anxieties about "their child securing employment" ($\chi^2(1)=7.33$, $p< .01$).

Figure 7. Worries and Anxieties about the Future

Figure8. ASD Group: Correlation between Worries/Anxieties about the Future and the Child's Age

4-2-4 Burdens and Anxieties concerning Care

Regarding burdens and anxieties concerning care, we found that a significantly greater number of parents struggled with or felt anxious about "finding friends for their child" in the ASD group than in the MR group ($\chi^2(1)=4.75$, $p< .05$). It can be suggested that this is related to the difficulty in forming friendships children with ASD experience as a result of their social difficulties. On the other hand, for children in the MR group, we found that parents struggled with or felt anxious about "care concerning bathing and voidance" ($\chi^2(1)=5.22$, $p< .05$). Looking at the results concerning the condition of the participants (Figures 1 and 3), we can assume that these results are due to the fact that there are many cases in which children with MR need more assistance in being independent and daily living [RC6]than children with ASD (Figure 9).

Regarding "finding friends for their child," no significant difference was seen within the ASD group even with age or the degree of the disorder. This is thus revealed to be a burden or anxiety common to parents of children with ASD regardless of their child's age or the degree of his or her disorder. Regarding burdens or anxieties concerning "care related to outings," which were common to both groups, in order to investigate the correlation to the presence of hyperactivity, those who answered "yes" were classified as the "hyperactive group," those who answered “no” were classified as the “not hyperactive group,” and these groups were then analyzed (Figure 10). The result of this analysis showed that in the ASD group parents with hyperactive children have a significant amount of burden and anxiety ($\chi^2(1)=6.13$, $p< .05$). In addition, regarding hyperactive ASD children, we saw that burdens and anxieties concerning “care related to going to school” were significantly greater compared to children who were not hyperactive ($\chi^2(1)=5.73$, $p< .05$).

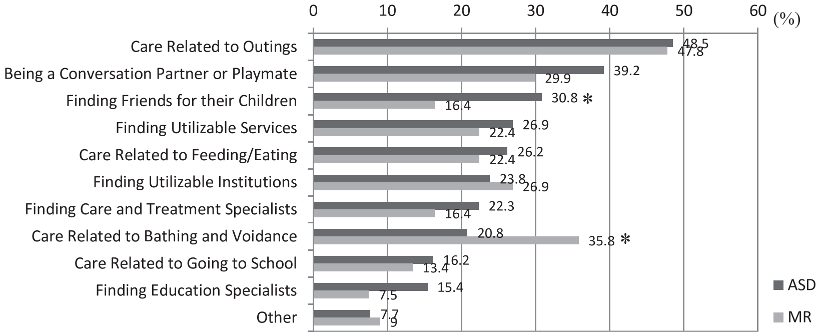

Figure 9. Burden and Anxieties concerning Care

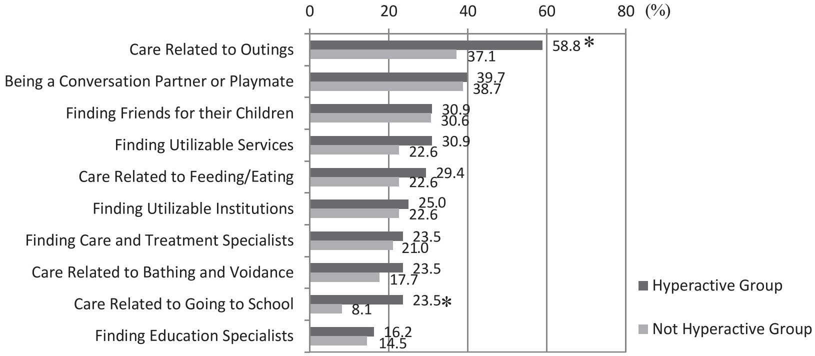

Figure 10. ASD Group: The Correlation Between Burdens/Anxieties concerning Care and Hyperactivity

4-2-5 Caregiver's Own Burdens and Anxieties

No significant difference between the two groups was seen in the burdens and anxieties reported by caregivers. The results showed that there were many parents (over 40%) who were burdened or felt anxious concerning "easily getting irritated" and "their own health." The next most common causes of burdens or anxieties were "having little time for myself" and "being unable to work," and we saw that these problems were common among parents regardless of the type of disorder.

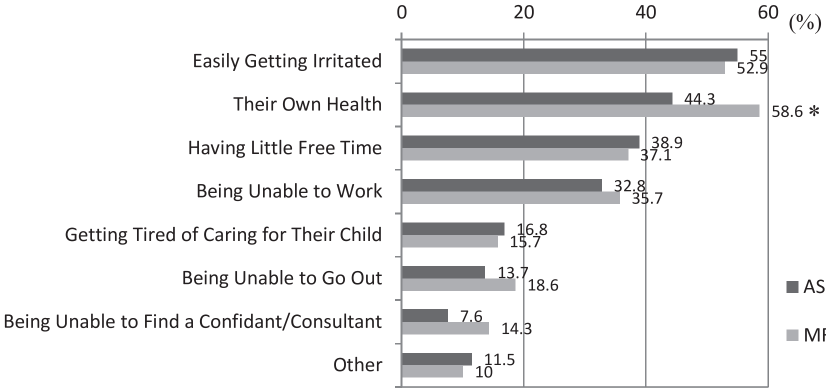

Figure 11. The Caregiver's Own Burdens and Anxieties

4-3 Desire for Economic, Lifestyle and Caregiving Support

4-3-1 Forms of Economic, Lifestyle and Caregiving Support Desired

We examined the support desired by parents focusing on "economic aspects," "lifestyle aspects," and "caregiving aspects." Also, in order to investigate whether the support the parents desired was related to the nature of their child's disorder, we classified the responses to the question regarding the degree of their child's communicative ability as putting them in the "communicates well group" if they replied "to communicate freely with anybody" or "to have no difficulty to talk to others" and in the "cannot communicate well group" if they replied "to communicate with others in simple ways" or "cannot communicate." Also, those who replied "yes" to the question of whether their children were hyperactive were classified as the "hyperactive group," and those who replied "no" were classified as the "not hyperactive group," and these groups were then analyzed. The results showed that regarding the desired economic support the MR group had a significantly greater desire for "securing employment for parents" than did the ASD group ($\chi^2(1)=9.86$, $p< .01$). The results also showed that up to 70% of parents in both groups desired an "improvement in the family allowance for children with special needs" (Figure 12).

Regarding what parents desired in terms of lifestyle support, we saw that a significantly greater number of those in the ASD group desired a "referral to an agency they could consult" ($\chi^2(1)=4.05$, $p< .05$) and "the introduction and dispatching of helpers" ($\chi^2(1)=4.05$, $p< .05$) than did those in the MR group (Figure 13). On the basis of this analysis it can be inferred that there is a greater lack of support provided by consultative agencies and helpers for children with ASD than there is for children with MR. Among these parents we also saw that a significantly greater number of parents of children with ASD who had difficulty communicating or were hyperactive desired the "introduction and dispatch of a helper" (communication: $\chi^2(1)=4.605$, $p< .05$; presence of hyperactivity: $\chi^2(1)=7.554$, $p< .01$). In addition, a significantly greater number of ASD children with communication difficulties desired the "expansion of 'respites' (a short-stay service)) ($\chi^2(1)=5.62$, $p< .05$), and a significantly greater number of parents of ASD children without communication difficulties desired the "expansion of places to receive consultation" ($\chi^2(1)=5.62$, $p< .05$). We can assume that this desire is strong because there are not enough agencies which provide specialized consultation regarding daily living for ASD children who do not have much difficulty communicating. On the other hand, for ASD children who show signs of severe disorders in communication or hyperactivity, the results show that many parents will request support that deals directly with their child, and want the assistance of helpers and “respites.” (Table 3).

Regarding what parents desired in terms of caregiving support, we saw that, compared to the MR group, a significant number of those in the ASD group desired an “increase in the number of consultants” ($\chi^2(1)=5.51$, $p< .05$) (Figure 14). These results showed that parents of children with ASD strongly desired consultants and agencies to consult with about matters involving their daily lives or caregiving.

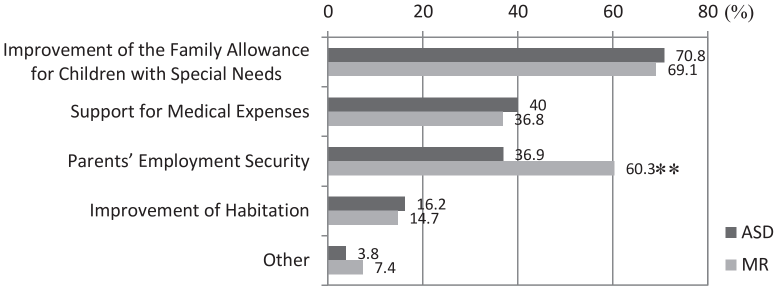

Figure 12. Desires regarding Economic Support

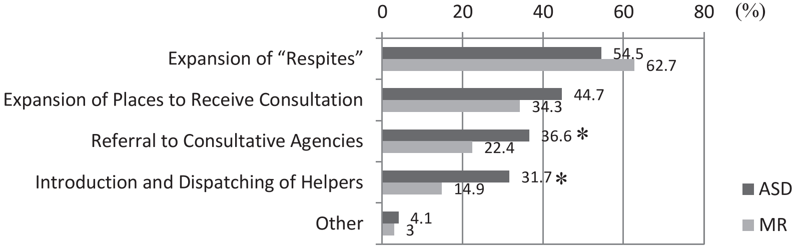

Figure 13. Desires for Support in daily life

Table 3. The Correlation Between Desires for Support in Daily Life and the Particulars of the Child's Disorder in the ASD Group

	Communication (N=128)		Hyperactivity (N=130)	
	Communicates Well	Cannot Communicate Well	Hyperactive	Not Hyperactive
Expansion of Places to Receive Consultation	61.8*	37.9	43.9	45.6
Expansion of Respites	38.2	62.1*	59.1	49.1
Referral to Consultative Agencies	32.4	36.8	34.8	38.6
Introduction and Dispatching of Helpers	17.6	37.9*	42.4**	19.3
Other	8.8	2.3	4.5	3.5

Note: Numerical values express the percentage in each group

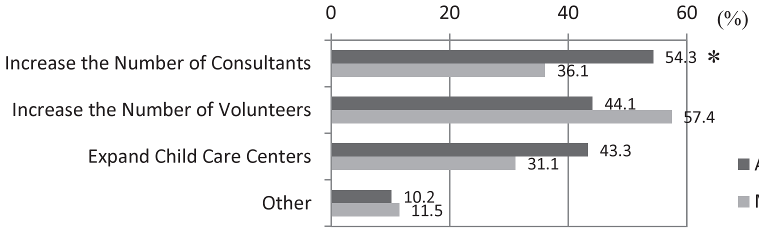

Figure 14. Desires for Caregiving Support

4-3-2 The Children's Future

Regarding parents' primary desire concerning their child's future, no significant difference was seen between the two groups; in both cases "live independently" was by far the most frequent response (Figure 15).

Figure 15. Primary Desire for the Child's Future

4-4 Detection and Notification of the Disorder

4-4-1 Timing of Suspicion/Noticing, Detection, Diagnosis, and Intervention/ Education

Regarding the timing of suspicion/noticing, detection, diagnosis and intervention/education regarding the disorder, for children with ASD the suspicion/ noticing period was around 1-2 years of age, the detection period was around 1-2 and 3-4 years of age, the diagnosis period was around 3-4 years of age, the intervention/education commencement period peaked at around 2-4 years of age, and a time lag was seen between each period (Figure 16). When it came to MR, on the other hand, there were many cases in which suspicion/noticing, detection and diagnosis occurred simultaneously within six months of the child's birth (Figure 17). In the case of MR, there are many disabled children with congenital chromosomal abnormalities such as Down's Syndrome where the disorder is evident at the time of birth.

Looking at the time span of the periods of suspicion/noticing, detection, diagnosis, and intervention/education (Table 4), in contrast to the MR group, where 73.1% of cases were diagnosed in less than a year, for over 60% (64.3%) of cases in the ASD group it took longer than a year. But it was found that there were more cases in the ASD group in which intervention/education began within a year of detection than in the MR group. Also, regarding the order of the diagnosis and the intervention/education commencement period (Table 5), in contrast to most cases in the MR group, where intervention/education took place after a diagnosis had been made, in the ASD group cases in which intervention/ education started before a diagnosis was made were most numerous, followed by cases in which the diagnosis and intervention/education occurred during the same period.

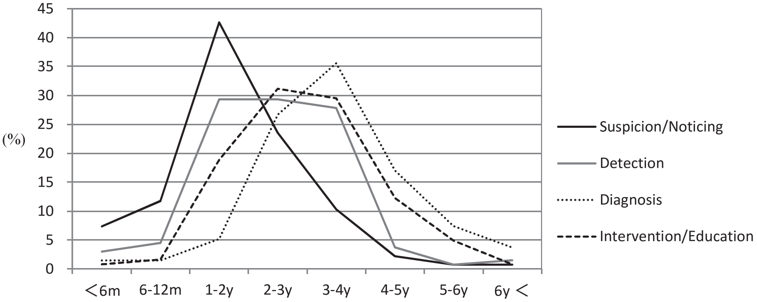

Figure16. Period of Suspicion/Noticing, Detection, Diagnosis and Intervention/ Education for the ASD Group (%)

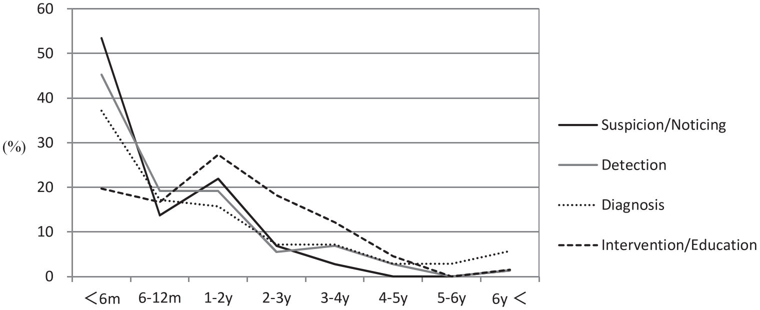

Figure 17. Period of Suspicion/Noticing, Detection, Diagnosis and Intervention/ Education for the MR Group (%)

Table 4. Timing of Suspicion/Noticing, Detection, Diagnosis, and Intervention/Education

			ASD	MR
Suspicion/Noticing Period	ASD=136, MR=73	＞ 2 Years Old	84(61.8)	65(89.0)
		2 Years Old ＜	52(38.2)	8(11.0)
Detection Period	ASD=135, MR=73	＞ 2.5 Years Old	70(51.9)	63(86.3)
		2.5 Years Old ＜	65(48.1)	10(13.7)
Intervention/ Education Period	ASD=122, MR=66	＞ 3 Years Old	64(52.5)	54(81.8)
		3 Years Old ＜	58(47.5)	12(18.2)
Diagnosis Period	ASD=136, MR=73	＞ 3 Years Old	47(34.8)	54(77.1)
		3 Years Old ＜	88(65.2)	16(22.9)
Period between Suspicion/Noticing and Diagnosis	ASD=133, MR=66	＞ 1 Year	24(18.0)	41(62.1)
		1 Year ＜	109(82.0)	25(37.9)
Period between Detection and Diagnosis	ASD=129, MR=67	＞ 1 Year	46(35.7)	49(73.1)
		1 Year ＜	83(64.3)	18(26.9)
Period between Suspicion/Noticing and Intervention/Rehabilitation	ASD=118, MR=64	＞ 1 Year	34(28.8)	21(32.8)
		1 Year ＜	84(71.2)	43(67.2)
Period between Detection and Intervention/Education	ASD=111, MR=62	＞ 1 Year	56(50.5)	24(38.7)
		1 Year ＜	55(49.5)	38(61.3)

Note: Numerical values indicate the number of people, and the percentage of each group is indicated in parentheses.

Table 5. Chronological Order of Diagnosis and Intervention/Education

	Intervention/ Education → Diagnosis	Intervention/ Education =Diagnosis	Diagnosis → Intervention/ Education	Total
ASD	48(36.6)	57(43.5)	26(19.8)	131(100)
MR	13(18.8)	25(36.2)	31(44.9)	69(100)

Note: Numerical values indicate the number of people, and the percentage of each group is indicated in parentheses.

4-4-2 The First Person to Suspect/Notice the Child's Disorder

Regarding the first person who suspected/noticed the child's developmental delay or disability (Figure 18), in contrast to the ASD group, where "mother" was overwhelmingly the most frequent response, in the MR group there were just as many replies of "doctor" as there were of "mother," a significantly higher result than in the ASD group ($p<$ .01, Fisher). This indicates that in the case of MR children the doctor and the mother suspected/noticed the child's abnormalities at birth during the same time period. In the ASD group, on the other hand, there were many cases in which "mother" was followed by "public health nurse," which showed a significant difference with the MR group ($p<$

.01, Fisher). Based on the fact that the suspicion/noticing period for the ASD group peaked at around 1-2 years of age, we can assume that the mother began to harbor suspicions that something was "strange" due to the manifestation of difficulties in verbal development and social interaction around this time. On the other hand, cases were also seen in which the disorder was noticed by a public health nurse at the child's 18-month health checkup even though it had not been noticed by the mother.

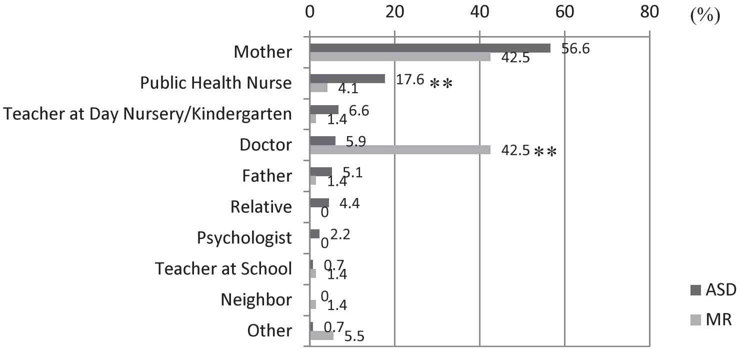

Figure 18. First Person to Suspect/Notice

4-4-3 Place Where the Child's Disorder was First Detected or Where the Parents Were Informed

Regarding the place where the child's developmental delay or disability was first detected/the parents were first informed (Figure 19), there were significantly more replies of "health care center" in the ASD group than in the MR group ($p<$ .01, Fisher), and in the MR group many replied "hospital" ($p<$ .01, Fisher). The period of detection forms a sloping mountain shape, with two peaks at the ages of 1-2 and 3-4, and this corresponds to the health checkups performed at the ages of 1 year 6 months and 3 years. On the basis of this observation we can see that health checkups play an extremely large role in the early detection of ASD in children.

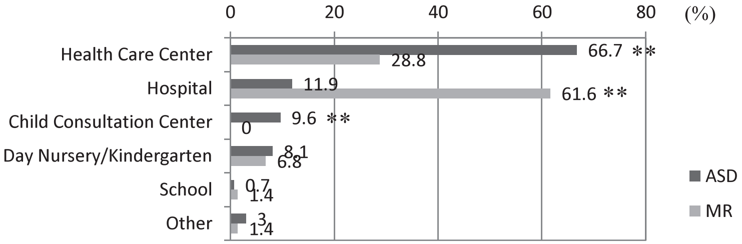

Figure 19. Place Disorder was First Detected or Parents were First Informed

4-4-4 Feelings at the Time of Notification/Diagnosis

Regarding parents' feelings when they were told the diagnosis, a significantly higher number of the parents in the ASD group felt "the diagnosis made sense" ($\chi^2(1)=11.55$, $p< .01$), "thought about how to cure the child" ($\chi^2(1)=4.82$, $p< .05$), and were "relieved that problems were not caused by parenting" ($\chi^2(1)=4.43$, $p< .05$) than in the MR group (Figure 20). Also, an analysis of the correlation between the feelings of the parents in the ASD group when they were notified of their child's diagnosis and the time periods for suspicion/noticing, detection, and intervention/education (Table 6) revealed that the longer the time span between suspecting/noticing that their child was "somehow strange" and detecting a disability the greater the tendency for the parents to feel that the diagnosis made sense when it was actually made (from suspicion/noticing until diagnosis: $\chi^2(1)=3.007$, $p< .10$; from detection until diagnosis: $\chi^2(1)=2.993$, $p< .10$). On the basis of this we can also see that although the parents of ASD children sensed that their children were "strange," they did not clearly understand the reason, and experienced anxiety and worry as they raised them. Conversely, there was a tendency for the parents who were notified within a year of suspicion/noticing and detection to feel a greater sense of shock than those who were notified one year or more afterward (from suspicion/noticing to diagnosis: $\chi^2(1)=2.956$, $p< .10$; from detection to diagnosis: $\chi^2(1)=3.801$, $p< .10$). Furthermore, in the relationship between intervention/education and diagnosis there was a tendency for fewer parents who had experience with intervention/education prior to receiving the diagnosis to feel shocked than those who started intervention/ education at the same time as, or after, notification ($\chi^2(1)=3.755$, $p< .10$).

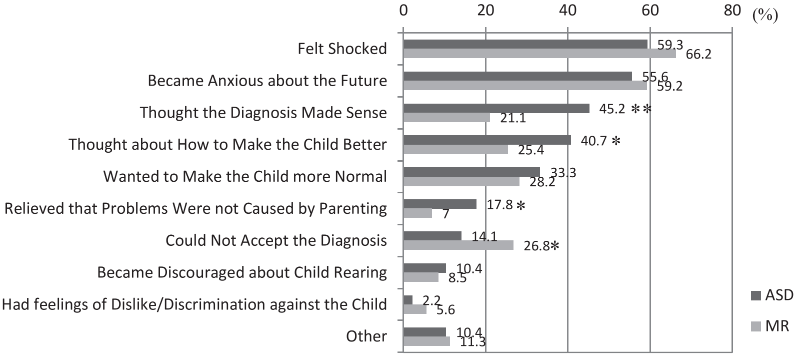

Figure 20. Feelings at the Time of Notification/Diagnosis

Table 6. Correlation Between Feelings at Time of Notification/Diagnosis and the Time Span of Suspicion/Noticing, Detection, and Diagnosis

	Suspicion/Noticing --Diagnosis		Detection--Diagnosis		Order of Intervention and Diagnosis	
	> 1 Year	1 Year <	> 1 Year	1 Year <	Intervention First	Simultaneous or Diagnosis First
Could Not Accept the Diagnosis	5(20.8)	14(12.8)	9(19.6)	10(12.0)	4(8.5)	14(16.9)
Felt Shocked	*18(75.0)†*	61(56.0)	*33(71.7)†*	45(54.2)	23(48.9)	*55(66.3)†*
Thought the Diagnosis Made Sense	7(29.2)	*53(48.6) †*	16(34.8)	*42(50.6)†*	24(51.1)	36(43.4)
Became Anxious about the Future	16(66.7)	58(53.2)	29(63.0)	44(53.0)	22(46.8)	50(60.2)
Relieved that Problems Were not Caused by Parenting	4(16.7)	20(18.3)	8(17.4)	16(19.3)	12(25.5)	12(14.5)
Became Discouraged about Child Rearing	3(12.5)	11(10.1)	7(15.2)	7(8.4)	5(10.6)	8(9.6)
Had Feelings of Dislike/ Discrimination against the Child	0(0.0)	3(2.8)	1(2.2)	2(2.4)	2(4.3)	1(1.2)
Wanted to Make the Child more Normal	7(29.2)	38(34.9)	15(32.6)	30(36.1)	12(25.5)	33(39.8)
Thought about How to Make the Child Better	11(45.8)	43(39.4)	20(43.5)	33(39.8)	18(38.3)	35(42.2)

Note: Numerical values indicate the number of people, and the percentage of each group is indicated in parentheses.

4-4-5 Good Points of Consultation at a Hospital or Special Institution

Regarding the good points of consultation at a hospital or special institution, a significantly higher percentage of parents in the ASD group replied “able to get good and specific advice on the disability/disorder” ($\chi^2(1)=6.96$, $p< .01$) than in the MR group (Figure 21). The parents of ASD children suspected that their children were “strange” at an early stage, and from the amount they worried about its cause and what to do about it we can surmise that receiving specific advice on their child’s disorder was of help to them when thinking about how to handle it.

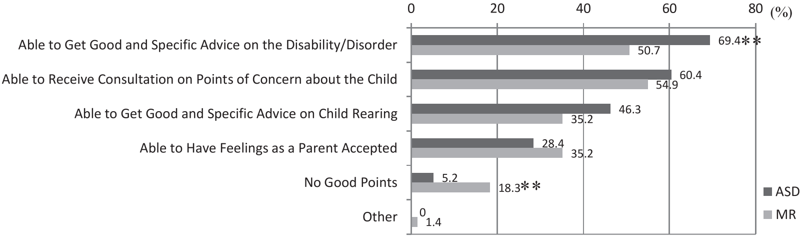

Figure 21. Good Points of Consultation at a Hospital or Special Institution

4-4-6 Desires concerning Hospitals and Special Institutions

Regarding their desires concerning hospitals and special institutions, a significantly higher number of parents in the ASD group wanted “make enough time for diagnosis and consultation” than in the MR group ($\chi^2(1)=8.798$, $p< .01$). This accords with the aforementioned desires for lifestyle and caretaking, and we can see that parents of children with ASD sincerely desire a person, place and time for consultation (Figure 22).

On the other hand, although a significant difference was not seen with the MR group, regarding “increase the number of specialist doctors,” which was the item most often desired by the ASD group, significantly more parents with children over 6 years old wanted this than parents whose children were under 6 years old (under age 6: 55.2%; over age 6: 73.5%; $\chi^2(1)=4.935, p< .05$) (Table 7). A possible reason for this is that the relationship with a medical system where it is possible to consult a specialist doctor weakens when the child reaches school age. Furthermore, the next highest reply, "suggest what the parents can do for their child," was desired in significantly more cases when the diagnosis was made late compared to cases when it was made early (diagnosed under the age of 3: 18.2%; diagnosed over the age of 3: 57.0%; $\chi^2(1)=6.121, p< .05$).

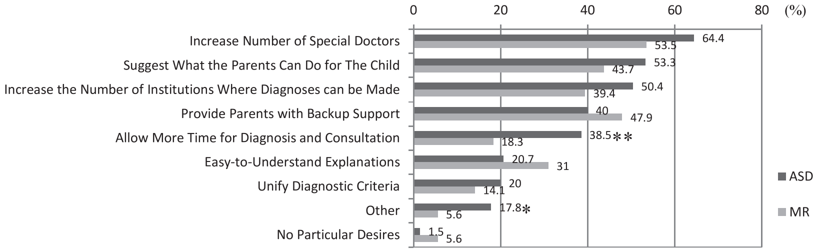

Figure 22. Desires concerning Hospitals and Special Institutions

Table 7. ASD Group: Correlation Between What is Desired of Hospitals and Special Institutions and the Child's Age/Period of Diagnosis

	Age (N=135)		Diagnostic Period (N=132)	
	Under Age 6	Age 6+	Under Age 3	Age 3+
Increase Number of Special Doctors	55.2	*73.5**	63.6	64.5
Suggest What the Parents Can Do for The Child	55.2	51.5	18.2	*57.0**
Increase the Number of Institutions Where Diagnoses Can be Made	47.8	52.9	36.4	51.2
Provide Parents With Backup Support	32.8	47.1	18.2	41.3
Allow More Time for Diagnosis and Consultation	37.3	39.7	36.4	39.7
Easy-to-Understand Explanations	23.9	17.6	9.1	22.3
Unify Diagnostic Criteria	19.4	20.6	27.3	19.8
Other	19.4	16.2	0	19
No Particular Desires	0	2.9	0	1.7

Note: Numerical values represent the percentages in each group

4-5 Early Intervention/Education for Children with these Disorders

4-5-1 Experience and Degree of Satisfaction with Early Intervention/Education

The percentage of children who had thus far received early intervention/education (including having temporary nursery teachers at a day nursery or kindergarten and parent-child play program) was 91.9% in the ASD group and 90.4% in the MR group. A high percentage of respondents in both groups had experience in this regard.

Regarding the degree of satisfaction with intervention and education, the percentage of parents who replied "very satisfied" or "satisfied" was 62.6% in the MR group and 65.8% in the ASD group, and there was no significant difference between the two groups (Figure 23).

4-5-2 Correlation between Degree of Satisfaction with Early Intervention/Education and Hospitals and Special Institutions

According to the previously mentioned results, among the ASD children there were many cases in which the child started an intervention or education program before, or during the same period as, their diagnosis. We therefore examined how the degree of satisfaction with the intervention/education was correlated to the good points of consultation at a hospital or special institution (Table 8). We classified the parents who replied "very satisfied," or "satisfied" to the question regarding their degree of satisfaction with the intervention/education as the "satisfied group," and those who replied "somewhat satisfied" or "not satisfied" as the "not satisfied group." These two groups were then analyzed. In both the ASD and MR groups, a significant percentage of parents who felt satisfied with the intervention/education replied "able to get good and specific advice on child rearing" (ASD group: $\chi^2(1)=5.592$, $p< .05$; MR group: $\chi^2(1)=5.228$, $p< .05$). Also, only in the ASD group did significantly more parents satisfied with the intervention/education reply “able to get good and specific advice on the disability/disorder” ($\chi^2(1)=4.045$, $p< .05$) and “able to have my feelings as a parent accepted” ($\chi^2(1)=8.899$, $p< .01$) than parents who felt dissatisfied. These results show that how the parents reacted to the intervention/education is related to how they felt when their child was examined at a hospital or special institution.

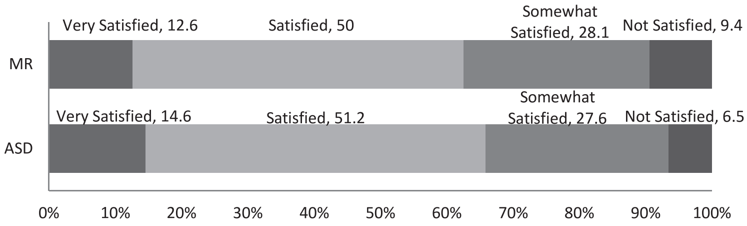

Figure 23. Degree of Satisfaction with Intervention/-Education

Table 8. Correlation between the Degree of Satisfaction with the Intervention/Education and Good Points of Consultation at a Hospital or Special Institution

Good Points of Being Examined	ASD (N=122)		MR (N=62)	
	Satisfied	Dissatisfied	Satisfied	Dissatisfied
Able to Get Good and Specific Advice on Child Rearing	*54.3**	31.7	*47.5**	18.2
Able to Get Good and Specific Advice on the Disability/ Disorder	*74.1**	56.1	52.5	50
Able to Have Feelings as a Parent Accepted	*38.3***	12.2	35	36.4
Able to Receive Consultation on Points of Concern regarding the Child	63	56.1	62.5	45.5
No Good Points	9.8	9.8	12.5	22.7

4-5.3 Location of Early Intervention or Early Education

Regarding the location of the early intervention or early education, the results showed that a significantly higher percentage of the MR group than the ASD group had the early intervention or early education in a “regular class at a day nursery/kindergarten” ($\chi^2(1)=4.598$, $p< .05$), a “hospital” ($\chi^2(1)=5.617$, $p< .05$) or a “special class at a day nursery/kindergarten” ($\chi^2(1)=4.238$, $p< .05$) (Figure 24). This suggests that compared to the MR group less support (including having temporary nursery teachers at a day nursery or kindergarten) is reaching children in the ASD group.

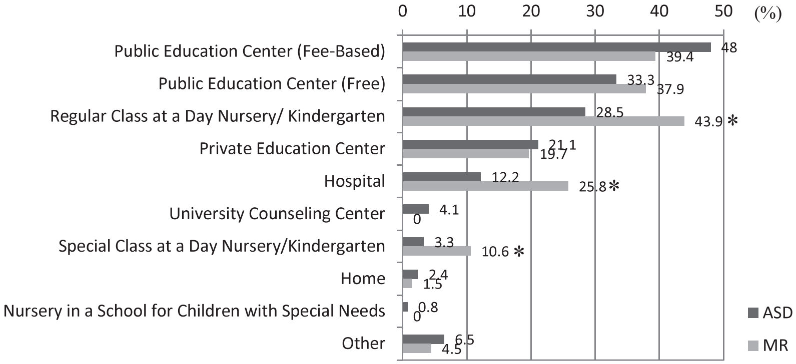

Figure 24. Location of Early Intervention or Early- Education

4-5-4 Burdens concerning Early Intervention and Early Education

Regarding the burdens concerning their child’s participation in early intervention/education programs, the most frequent reply from parents in both groups was “time” (Figure 25). The next most frequent reply was “there was little burden” for the ASD group, but for the MR group it was “human resources”, and there was a significantly higher number of parents giving this response in the MR group than in the ASD group ($\chi^2(1)=8.243$, $p< .01$). As a result of investigating whether there was a correlation between burdens concerning the intervention and degree of satisfaction (Table 9), we found that a significant number of parents who felt dissatisfied with the intervention program replied “human resources” (χ^2 (1)=8.562, p=.003 <.01) and “time” (χ^2(1)=4.102, $p<.05$) when asked about burdens in this area.

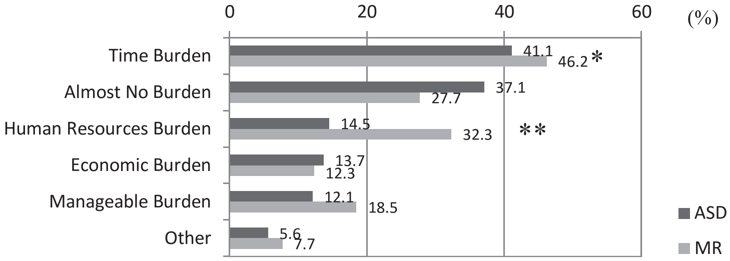

Figure 25. Burdens concerning Early Intervention and Early Education

Table 9. Correlation between Degree of Satisfaction with the Intervention/Education and Related Burdens for Parents of ASD Children

		Degree of Satisfaction with the Intervention/ Education	
		Satisfied	Dissatisfied
Burden on Intervention/ Education	Human Resources Burden	6(7.4)	*11(26.8)***
	Economic Burden	11(13.6)	6(14.6)
	Time Burden	28(34.6)	*22(53.7)**
	Manageable Burden	12(14.8)	3(7.3)
	Almost No Burden	33(40.7)	12(29.3)

4-5-5 Good Points of Receiving Early Intervention/Education

Regarding the good points of receiving early intervention/early education, in both groups “parents were able to learn how to interact with the child” was the most frequent reply, followed by “the child developed” (Figure 26). On the other hand, compared to the MR group, a significantly lower number of parents in the ASD group replied “child was able to make friends” (χ^2(1)=8.243, $p<.01$). These results suggest that participation in early intervention and early education was a good opportunity for parents to learn how to interact with their children, and for the children it was a valuable chance for them to develop as well. On the other hand, it is clear that it was difficult for the children in the ASD group to make friends.

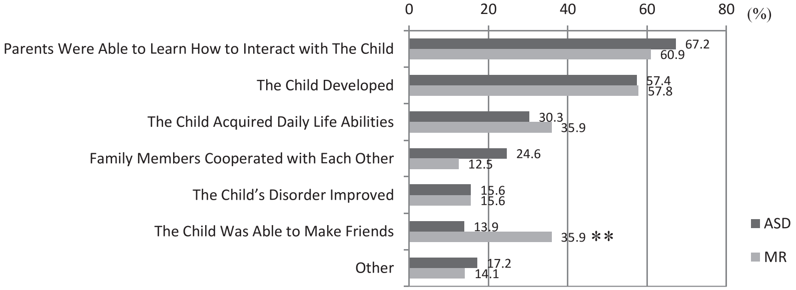

Figure 26. Good Points of Receiving Early Intervention/-Education

4-6 Support Received and Support Desired

4-6-1 Person Consulted the Most on Developmental Support

Regarding support for the child's development, for the person a parent consults the most, "spouse" was the most frequent reply in both groups (Figure 27). The next most frequently consulted person was "teacher at an institution" for the ASD group, and this was significantly higher than the MR group ($p< .05$, Fisher). In contrast, the next most frequently consulted person for the MR group was "teacher at school," and this was a significantly higher result than for the ASD group ($p< .01$, Fisher). Also, in comparison to the ASD group, a higher percentage of the MR group replied "doctor" ($p< .10$, Fisher).

Next, we examined whether there were any differences in who is consulted based on the child's affiliation (Table 10). The results of this analysis showed that for parents of pre-school age children in the ASD group "teacher at an institution" was the most frequent response, followed by "spouse." On the other hand, for parents of pre-school age children in the MR group, "spouse" was the most frequent, followed by "teacher at an institution." For parents of children in the ASD group attending special needs classes, "spouse" was the most frequent response, followed by "friend" and "psychologist." Only a small percentage of parents (5.6%) chose "teacher at school." Conversely, for parents of children attending special needs classes in the MR group, "teacher at school" was the most frequent answer, followed by "spouse" and "psychologist." For the parents of children attending a school for special needs in the ASD group, "spouse" was the most frequent reply, followed by "teacher at school." For parents of children attending a school for special needs in the MR group, "spouse" and "teacher at school" responses appeared in equal proportions. Finally, for the parents of children attending regular classes in the ASD group, "psychologist" was the most frequent reply, and "teacher at school" responses were uncommon at 9.1%.

This analysis shows that for pre-school children with ASD, teachers at institutions serve as people to consult on developmental support on an equal level with the spouse. After the child starts school at a school for special needs, teachers at the school are second to the spouse as people consulted, but in the special needs classes and regular classes the teachers at the school are rarely consulted. It was shown that, in their place, there is a strong tendency for friends and psychologists to be second to the spouse as the person most often consulted.

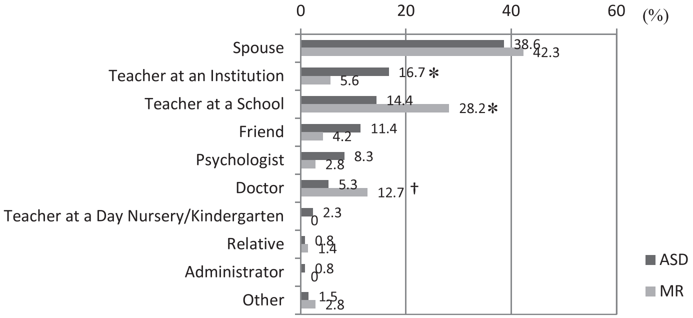

Figure 27. Person Consulted the Most on Developmental Support

Table 10. Person Consulted on Developmental Support and the Child's Affiliation

			Spouse	Relative	Friend	Doctor	Psychologist	Preschool/ Kindergarten Teacher	School Teacher	Institution Teacher	Total
Pre-School	ASD	n	18	1	4	2	5	3	0	21	54
		%	33.3	1.9	7.4	3.7	9.3	5.6	0.0	38.9	100.0
	MR	n	13	0	0	2	0	0	0	4	19
		%	68.4	0.0	0.0	10.5	0.0	0.0	0.0	21.1	100.0
Regular Class	ASD	n	2	0	2	2	3	0	1	0	11
		%	18.2	0.0	18.2	18.2	27.3	0.0	9.1	0.0	100.0
	MR	n	0	0	0	0	0	0	1	0	1
		%	0.0	0.0	0.0	0.0	0.0	0.0	100.0	0.0	100.0
Special Needs Class	ASD	n	8	0	5	1	3	0	1	0	18
		%	44.4	0.0	27.8	5.6	16.7	0.0	5.6	0.0	100.0
	MR	n	3	0	0	0	2	0	5	0	11
		%	27.3	0.0	0.0	0.0	18.2	0.0	45.5	0.0	100.0
School for Special needs	ASD	n	23	0	3	2	0	0	17	1	48
		%	47.9	0.0	6.3	4.2	0.0	0.0	35.4	2.1	100.0
	MR	n	14	1	3	7	0	0	14	0	40
		%	35.0	2.5	7.5	17.5	0.0	0.0	35.0	0.0	100.0

4-6-2 Support Received

Regarding support currently received, "support for the child's development" was the most frequent reply in both groups (Figure 28). Compared to the MR group, the results show that in the ASD group a significantly greater number of people replied "support for the child's disorder" ($\chi^2(1)=5.062$, $p< .05$). On the other hand, compared to the ASD group, there were significantly more "support for learning" ($\chi^2(1)=4.569$, $p< .05$) responses in the MR group.

We examined whether there was a correlation in the ASD group between the support received and the child's age and affiliation (Table 11). The results of this analysis showed that there were significantly more children under the age of 6 receiving "support for the child's development" than those 6 years of age and older ($\chi^2(1)=11.689$, $p< .01$). On the other hand, among children 6 years of age and older, significantly more received "support for learning" ($\chi^2(1)=19.697$, $p< .01$) and "support for decreasing the burden on the family" ($\chi^2(1)=15.888$, $p< .01$) than children less than 6 years old. Furthermore, among those who responded “support for the child’s development” and “support for learning” there was no significant difference seen between regular classes, special needs classes, and schools for special needs, but among those who responded “support for the child’s disorder,” it became clear that there were significantly fewer whose children were attending regular classes ($\chi^2(2)=10.402$, $p< .01$).

Table 11. The Correlation Between the Support Children with ASD Receive and their Age and Affiliation

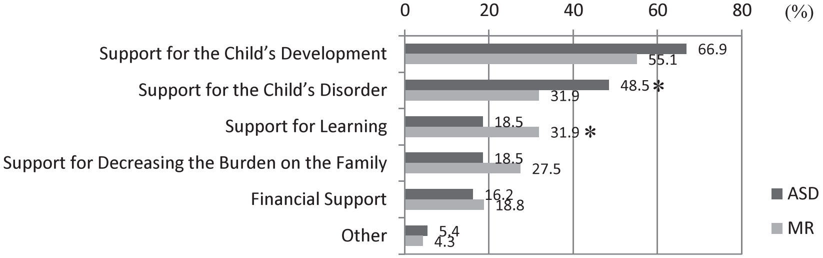

Figure 28. Support Received

	Age (N=130)		Affiliation After Starting School (N=74)		
	Less than 6 years old	6 years old and older	Regular Class	Special Needs Class	School for Special Needs
Support for the Child’s Disorder	32(50.0)	31(47.0)	0(0.0)**	9(52.9)	24(52.2)
Support for the Child’s Development	52(81.2)**	35(53.0)	9(81.8)	8(47.1)	23(50.0)
Financial Support	10(15.6)	11(16.7)	0(0.0)	5(29.4)	8(17.4)
Support for Learning	2(3.1)	22(33.3)**	4(36.4)	8(47.1)	10(21.7)
Support for Decreasing the Burden on the Family	3(4.7)	21(31.8)**	0(0.0)	4(23.5)	17(37.0)
Other	5(7.8)	2(3.0)	1(9.1)	1(5.9)	3(6.5)

Note: Numerical values indicate the number of people, and the percentage of each group is indicated in parentheses.

4-6-3 Support Being Sought

“Improvements concerning specialist staff” had the most responses in both groups (Table 29). On the other hand, responses of “support for the child’s development” ($\chi^2(1)=5.075$, $p< .05$) and “support for (the child) making friends and playmates ($\chi^2(1)=4.012$, $p< .05$) were significantly more numerous in the ASD group than in the MR group. In the ASD group “support for the child’s development” was the most frequent form of support currently received, but we can see that other forms of support were desired as well. Also, regarding “support for (the child) making friends and playmates,” “finding friends for the child” appeared in the responses concerning burdens and anxieties regarding caregiving. In addition, considering that few parents replied “was able to make friends” when asked about the “good points of receiving early intervention/education,” we can see that they strongly desired support related to making friends as this is a problem that ASD children often have.

We investigated whether there was a correlation between the support desired and the child’s age and their affiliation after starting to attend school in the ASD group (Table 12). We found that more parents with children 6 years old and older desired “financial support” than those with children less than 6 years old ($\chi^2(1)=2.888$, $p<.10$). In the correlation between their affiliation after they started attending school and the support desired, “support for the child’s disorder” was desired for children with ASD enrolled in schools for special needs, special needs classes, and regular classes (presented in order from the highest to lowest percentage) ($\chi^2(2)=8.349$, $p< .01$). In contrast, “support for making friends and playmates” was desired for children with ASD enrolled in regular classes, special needs classes, and schools for special needs (presented in order from the highest to the lowest percentage) ($\chi^2(2)=11.557$, $p< .01$). From these results we can see that it is difficult for these children to make friends and playmates in regular classes. Furthermore, we can see that a significantly greater number of parents of children enrolled in schools for special needs desired “support for decreasing the burden on the family” ($\chi^2(2)=9.697$, $p< .01$).

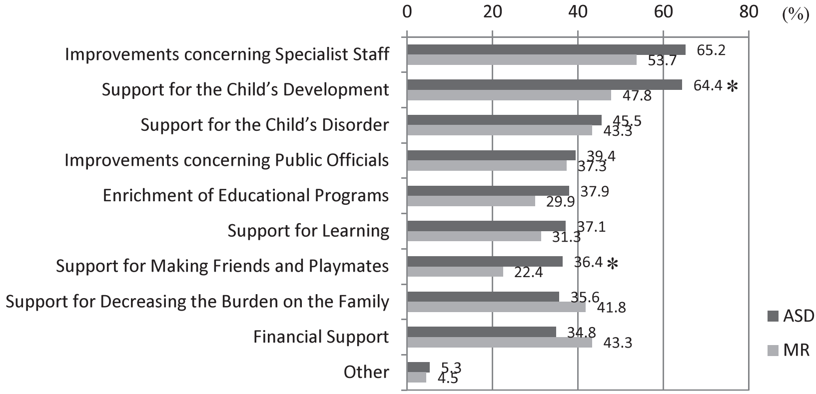

Figure 29. Support Desired

Table 12. ASD Group: Correlation between Support Desired and the Child’s Age and Affiliation after they Started Attending School

	Age (N=132)		Affiliation After Starting School（N=76）		
	Less than 6 years old	6 years and older	Ordinary Class	Special Support Class	Special Support School
Support for the Child’s Disorder	26(40.0)	34(50.7)	2(16.7)	7(38.9)	*28(60.9)***
Support for the Child’s Development	45(69.2)	40(59.7)	7(58.3)	10(55.6)	29(63.0)
Financial Support	18(27.7)	*28(41.8)†*	2(16.7)	6(33.3)	22(47.8)
Support for Learning	27(41.5)	22(32.8)	7(58.3)	5(27.8)	13(28.3)
Support for Making Friends and Playmates	21(32.3)	27(40.3)	*9(75.0)***	10(55.6)	12(26.1)
Support for Decreasing the Burden on Family	23(35.4)	24(35.8)	2(16.7)	2(11.1)	*22(47.8)***
Enrichment of Educational Programs	26(40.0)	24(35.8)	6(50.0)	9(50.0)	13(28.3)
Improvements Concerning Specialist Staff	44(67.7)	42(62.7)	7(58.3)	10(55.6)	31(67.4)
Improvements Concerning Public Officers	25(38.5)	27(40.3)	4(33.3)	7(38.9)	19(41.3)
Other	3(4.6)	4(6.0)	0(0.0)	2(11.1)	3(6.5)

Note: Numerical values indicate the number of people, and the percentage of each group is indicated in parentheses.

5. Conclusion

5-1 Support Desired for Daily Life and Caregiving

Compared to parents of children with MR, among parents of children with ASD more cases were seen in which, in addition to consulting with their spouse, they also received consultation on daily living, educational and medical matters at a place close to them, such as a school or institution that their child attends. When we looked into who they were consulting on developmental support, in most cases where a teacher at an institution was consulted the parent had a child of pre-school age, and in a majority of the cases where a school teacher was consulted the parent had a child attending a school for special needs. Among parents of children attending special needs classes and regular classes, the school teacher is rarely the one consulted; in most cases, it is the spouse. In cases where someone other than a spouse was chosen, a friend or psychologist was the one consulted in place of a school teacher. From these results, we can see that for the parents of children with ASD attending special needs classes or regular classes, there are few people close to them on whom they can rely besides their spouse. Furthermore, even if they can rely on their spouse or a place close at hand such as their child’s school or institution, it became clear that this is not enough and that they desire places and people who can give them specialized and specific advice on how to deal with their child’s disorder.

We also saw that in cases of severely disabled children with ASD many parents desired support that deals directly with their child; they did not want only agencies they could consult but also “respites” and helpers.

5.2 Support Desired in the Periods of Suspicion/Noticing, Detection, Diagnosis, and Intervention/Education

Most parents of children with MR experienced suspicion, detection, and diagnosis within six months of their child's birth, and intervention/education was received in less than a year. In children with ASD, in contrast, it has been shown that there is a time lag between the periods of suspicion (1-2 years old), detection (from 1-2 years old to 3-4 years old), starting intervention/education (from 2-3 years old to 3-4 years old) and diagnosis (3-4 years old).

In the case of children with ASD, in many cases the mother started to become suspicious when a delay in verbal development and difficulties in social interaction being to gradually manifest when the child was around 1-2 years old. On the other hand, there were cases in which the disorder was detected around this time at the health checkup performed at the age of 1 year and 6 months, so there are also parents who experienced suspicion and detection at the same time. We can surmise from their feelings after diagnosis that the period from becoming suspicious is an extremely painful time for the parents. Even if during this period they detect a "difficulty" or "strangeness" in their children unlike that of other children, they continue to raise their child without understanding its cause, worrying about how to interact with their child, and blaming themselves and their parenting. Therefore, when their child's disorder becomes clear after diagnosis, they accept the diagnosis and feel relieved that the way they raised their child was not the cause. On the other hand, we must take into consideration the fact that, no matter the circumstances, receiving the diagnosis is a large shock to the parents. For that reason, while acknowledging the parents' burden and anxiety when they are given the diagnosis, at the same time provision of specific and detailed advice on their child's disorder is necessary.

Furthermore, between suspicion and detection and diagnosis, receiving early intervention and early education is important for decreasing the parents' anxiety and suffering as well as increasing their acceptance of the disorder. It has been shown that early intervention and early education is an opportunity for the parents to learn how to interact with their child specifically, and, at the same time, it is also an opportunity for the child to undergo important development. Also, it is clear that the degree of parents' satisfaction with early intervention and early education programs is linked to their feelings when they receive consultation at a hospital or special institution.

Taking the aforementioned points into consideration, appropriate responses by specialists at the time of notification and early intervention are needed. At the same time, ongoing emotional support for parents, beginning in the "suspicious" period, and the establishment of a support system that makes the transition from suspicion and detection to early intervention a smooth one are also necessary.

5.3 Children's "Friendships"

Parents desiring support in finding friends and playmates for their child were significantly more numerous in the children with ASD group, and finding friends was listed as a source of burden and anxiety in caregiving. Furthermore, regarding early intervention and early education, compared to children with MR, the reality is that it is difficult for them to make friends, and significantly fewer children in the ASD group than in the MR group receive support, such as having temporary nursery teachers, at a day nursery school, kindergarten or regular class. These facts suggest that difficulty in "making friends" is a common problem among children with ASD, and make clear that in addition to being a cause of burdens and anxiety for parents, it is also an area where they would like support.

Early intervention and early education are important forms of support for the parents of children with ASD, who are burdened by the aforementioned time lag from suspicion to diagnosis, and, at the same time, they also provide essential developmental support for the child. During this period, in addition to providing specialized support at the daycare or education site where the child spends the majority of the day, it is also necessary to support the broadening and deepening of friendships, a difficult area for children with ASD.

5.4 Developmental Support for the Child

"Support for the child's development" and "support for the child's disorder" are the forms of support most often received, and these are forms of support that will be required in the future as well. In particular, "support for the child's development" was desired significantly more often among the parents of children with ASD than among the parents of children with MR. In the case of children with ASD, it is surmised that the parents will always hold on to the hope and expectation that due to the disorder's characteristics it may disappear or decrease. Therefore, they hope for their child's development and growth, and we can assume that they will strongly demand the ability to receive support for development in the future as well. This expectation and desire particular to parents of children with ASD, in contrast to parents of children with MR, can be seen in the area of "worries and anxieties about the child's future," where they expressed hope that their child will get married and secure employment.

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