Research on Families Having Children with Developmental Disorders in Vietnam: Questionnaire and Interview Survey Given to Parents

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1. INTRODUCTION AND OBJECTIVES OF THE STUDY

1.1. Background of the study

Family plays an important role in raising and educating children with developmental disabilities in general and with autism in particular. Family's economic status, condition of care, condition of education, care-giver worries on caring have direct impact on the development of children with developmental disabilities including autism. Families having children with developmental disorders often face difficulties in caring and educating their children.

Families with children with developmental disabilities are often in need of support and help for the children and care-givers from society, social organizations, and experts. The supports they need include knowledge and skills on caring and educating the children, counseling/help for daily life, and supporting services.

In Vietnam, recently the number of children diagnosed with developmental

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disorders including autism has been increasing, especially in big cities. There has been an increased demand from parents having children with developmental disorders to have information on caring for the children, available medical and supporting services, and institutions/centers for special education for children with developmental disabilities. For parents, it is not always easy to access to needed information, existing supporting and education services.

In the last decade, the special education in Vietnam has developed substantially. Intervention and educational services including special schools, special education centers for children with developmental disabilities has been increased by governmental sectors, social organizations, private organization, NGOs, education institutions. Policies on social welfare and social support for disabled children have been improved. The efforts of government and society have responded partly to the need and demand of children with disabilities in general and with developmental disorder in particular and their families. There is, however a gap between the need of families and response of the society. Many special education institutions do not have enough services for children and families. The number of institutions/schools having integrated education is still limited. There is also a lack of teachers and staff for special education. Social welfare and economic support provided to families with children with developmental disorders are still limited. How to respond to the need and demand of families having children with developmental disorder is a question that needs to be answered.

There have been number of research studies with children having developmental disorders including autism; however there is still a lack of research studies on the difficulties, the needs of families. It is important to carry out such research study in order to provide evidence for improving the support system and services for children with developmental disorders and their families.

From March 2009 to February 2010, a research study entitled "Survey for Family of Children with Disability in East Asia" was conducted in Ha Noi and Ho Chi Minh city (HCMC). That pilot study was a part of a research program exploring needs of families with children with developmental disorders in East Asia among Japan, China, and Vietnam.

1.2. Objectives of the study

The aim of the study was to clarify the needs for children with disability and their family, and to investigate the better way to support. Specific objectives are following:

- Identify needs of families having preschool and school-age children with developmental disorders;
- Provide a description of early detection and intervention and identify related factors for children with developmental disorders;
- Explore perception of parents towards current supporting programs for children with developmental disorders.

2. METHODOLOGY

2.1. Overall study design

A cross-sectional survey design was employed in this study. Self-administrated questionnaire was employed (The parents of children with disabilities filled the questionnaire with support from teachers and field supervisors).

Leading researchers from China, Japan and Vietnam had at least 3 meetings to develop a common questionnaire with careful consideration of a cross-cultural factor, professional terms, and social situation of each country. The first questionnaire version 4.2 was implemented in each country as a pilot survey. In Vietnam, we conducted a pilot investigation from March to May 2009 on 31 parents of children with ASD in Ha noi. Each country had an opportunity to present the results of their pilot investigation on the Seminars in Hanoi in June and November 2009. Based on results from piloting, we modified the first draft version 4.2 and went to the final version. Since December 2009 to March 2010, in Vietnam we have done our final investigation on parents of children with developmental disorders from some Schools/Institutions/Day-cares at the two big cities of Vietnam, Hanoi and HCMC.

2.2. Sample size and location

254 parents of children diagnosed with developmental disorders, including 154 parents from Hope Center No 1, Sea Star Center, Khanh Tam Center, Light Star Center in Hanoi and 100 parents from Binh Minh special school, Gia Dinh school, Dream school, Suong mai kindergarten in HCMC.

The international research group agreed that each country took the big cities as sampling to do this research. Therefore in Vietnam, Hanoi and HCMC was chosen as study locations. All schools, kindergartens, centers and institutions in this research were randomly selected.

2.3. Data collection methods

2.3.1. Questionnaire

Self-administrated questionnaire with support from teachers was the main data collection method.

One questionnaire was developed in English. The questionnaire was translated into Vietnamese and was adapted where necessary to be suitable to local and cultural contexts.

The questionnaire was piloted with 31 respondents in Hanoi. After piloting the survey questionnaire was revised and finalized.

Questionnaire includes face sheet: with basic information about participants. There are two parts: Part 1: about needs for family including: financial state of family; worries in daily life; condition of care; support that parents wish for; about child's future. Part 2: about developmental support for child with ASD including: detection and diagnosing of child's disability; early intervention and education for child.

A training course on the objectives, content and structure of questionnaire and data collection for a group working at faculties of special education at Hanoi National University of Education and Ho Chi Minh City University of Pedagogy was conducted. Those people served as data collectors for the study.

2.3.2. Interview

Life-Line Interview (LIM) and Semi-Structured Interview Methods were used in this study for data collection.

2.3.2.1. LIM

LIM was used to investigate an individual's perception of their lives by recalling the events and experiences in life. This is a special method to understand the interviewee's vicissitudes in the life till now. The events of vicissitudes are different from each interview participant. The advantage of using LIM is a tool to describe the emotions of the participants. The researchers are able to obtain accurate data that are described on the same sample. The interviewer can measure the life vicisstudes of the participants through drawing and describing in words.

LIM focuses on late stage in adulthood, middle-aged or three age groups (early, middle and late adulthood). Life-line starts at birth and continues through present or future.

The factors that affect and change the vicissitudes in Life-Line graph are events or problems, unexpected experience of individual.

Procedure: Using LIM through out 4 steps
Step 1: Introduction of LIM
Step 2: Explaination of Life-Line
Step 3: Drawing and explaining from birth to present

- Participants draw their Life-Line starting at their birth points and ending at present.
- Participants write their age in each top and bottom point in diagram
- Participants speak about events occuring in certain points or throughout a described period.

Step 4: Drawing from present to dead time

LIM interview tool

- A paper in A4 size
- A square paper with 286mm in length
- A rectangle paper with 174mm in width

Interview guiding

Interviewer questions about occurred events that illustrated in up and down points in line graph. Based on line graph, interviewer understands what are important events in participants' lives, what are dispairs in their lives and what and how do they overcome those shocked events. (See S. CASE STUDY for focused points in line graph). With up and down line, such questions were asked, such as, "Could you explain about this event or any experience in this period?" "What supports did you receive in this period?" for the increasingly line.

2.3.2.2. Semi-Structured Interview

Focusing on the crisis and transition periods in the education system. The content is designed beforehand.

Guidelines for semi-structured interviews

- Interview about the events and experiences that the parent went through because sometimes it is difficult for them to answer about their feelings of that experience.
- Carry out interviews with an understanding of the emotional complexity that parents can not easily pass for the diagnosis.
- Questions should be clear, easy to answer.
- Using the kinds of questions that are easy to answer and that are easy to awaken old memories. For example, before knowing your child's problems, where did you come for advising? What did you talk with them about your child? What did you do to find school for your child?

2.4. Data analysis

Epidata software was used for data entry. Data were entered twice (double entry) to ensure the accuracy. Data then were transferred into SPSS data files for analysis.

SPSS 16.0 software were used for data analysis. The analysis included monitoring analysis: descriptive analysis to provide the baseline level of behaviors and determinants.

2.5. Ethical issues

Potential risks to respondents were minimal. The focus of this baseline study was explore knowledge, experiences, opinions on children with disabilities, detection/diagnosis, and intervention.

An informed oral consent and assent procedure was implemented for recruiting all respondents. Before filling the questionnaire and interviewing, the teachers introduced the objectives of the study, the confidential nature of information collection to the participant. Participants were also informed that they had right to decline to participate in the study without any consequences and that they could refuse to answer any questions, and stop participating in the study any time without suffering in any way. Interviewer signed the informed consents after participants agreed to participate in the interview to confirm their voluntary participation.

Participants filled the questionnaires and participated in interview in private to ensure confidentiality and privacy. No photographs were taken of the respondent or family.

Data collected from study subjects did not include any identifying information, such as name or address.

Every effort was made to protect the confidentiality and the identity of study subjects. All completed questionnaires and interviewed productions were stored in locked file cabinets and only essential study personnel had access to the data.

3. QUESTIONNAIRE FINDINGS

3.1. Characteristics of the sample

A total of 254 parents of children diagnosed with developmental disorders participated in the study.

The sample consists of 81.7% parents of male disabled children and 18.3% parents of female disabled children. Disabled children less than 6 year-old account for 80% and children 6 year or older account for 20% of the total sample (Table 1).

Table 1. Children's characteristic

Characteristics	Ha Noi		Ho Chi Minh		Other provinces		Total	
	Freq	Percent	Freq	Percent	Freq	Percent	Freq	Percent
Child's Gender								
Male	115	81.6	76	79.2	14	100	205	81.7
Female	26	18.4	20	20.8	0	0	46	18.3
Age categories***								
<6 year-old	125	87.4	63	66.3	13	100	201	80.1
>6 year-old	18	12.6	32	33.7	0	0	50	19.9

*Note: ***P-value<0.001*

About two-third of the children were at institutions, daycare centers, schools for children with special needs: Fifty-five percent of the children were at schools for special needs, 5.5% were at institution/daycare for preschool children with special needs, 2.4% were at institution/daycare for school children with special needs. 22.5% disabled children studied at kindergartens, 7.5% were at elementary schools, and about 4% were at home (Figure 1).

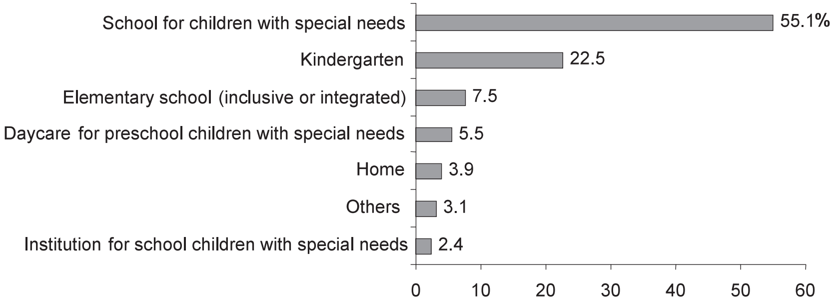


Figure 1. Education place where children belong to

Regarding the types of disability, Autism, verbal development delay, and intellectual disability were three main types: 37% children were diagnosed with Autism or Asperser syndrome, 27% with delay of verbal development, and 19% with intellectual disability. Apart from three main types of disability, 4.7% children were diagnosed with developmental disorder (ADHD and/or LD), 4.7% with physical disability, and 4% with behavioral problems (Figure 2).

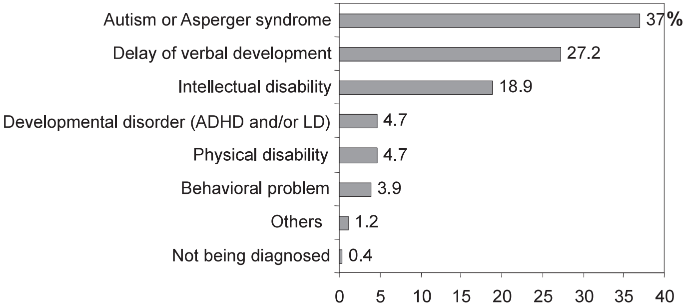


Figure 2. Types of children's disabilities

3.2. Condition of disability

Twenty-seven percent children needed help totally for their basic activities (eating, clothing, and moving), 59% needed help partially, and 14% did not need support for basic activities. Higher proportions of children under 6 years needed support for their basic activities than children older than 6: 30% children under 6 needed support totally compared with 14% children older than 6 did; 61.7% children under 6 needed partial support compared with 48% children older than 6; 38% older children did not need support for their basic activities compared with 8% children under 6 (the difference is statistically significant with $P < 0.001$). Clearly, this difference is due to part of disability and also part of the nature of age as little children need more help and support than older children (table 2).

For 12% of the children, it was impossible to communicate with other and 77% children could only communicate with other in a simple way. Only 7% communicated with other freely and for 4% it was not difficult to talk with other. There is no significant difference in terms of communication ability between children less than 6 and children older than 6.

Regarding support and help needed for daily life, 31% needed help all of the time, 35.5 needed help partially, 25.4% needed help when facing new situations, and for only 8% there was no difficulty for daily life (table 2).

Among the disabled children, 57% were considered by mother/father/guardians as hyperactive children and children less than 6 had higher proportion of being hyperactive than children older than 6 (60% vs. 46%, with $P< 0.05$). Among the hyperactive children, 64% needed to be watched all of the time and 36% needed to be taken care partially.

Table 2. Condition of disability by age group

Indicators	Child’s age		Total
	< 6 ages	> 6 ages	
Help needed for basic activities***			
Totally	29.9	14.0	26.7
Partially	61.7	48.0	59.0
Not needed	8.4	38.0	14.3
Difficulty in communication			
Communicate freely	6.1	10.0	6.9
No difficulty to talk with others	4.6	0	3.7
Communicate in simple way	76.5	80.0	77.2
Impossible	12.8	10.0	12.2
Difficulty in daily life			
No difficulty	6.1	14.0	7.7
To be helped partially	34.3	40.0	35.5
To be helped when facing new situation	25.8	24.0	25.4
To be helped all the time	33.8	22.0	31.5
Hyperactive child*	59.9	46.0	57.1
Hyperactive child need to be watched all of the time	67.5	47.8	64.3
Hyperactive child need to be taken care partially	32.5	52.2	35.7

*Note: * P <0.05; *** P <0.001*

3.3. Needs for family

3.3.1. Financial state of family

3.3.1.1. Person earning living expenses mainly

In 53% households, both mother and father earn living expenses for the family, father was the main person responsible for living expenses in 37% households, and mother earned living expenses mainly in 6.7% households (Figure 4).

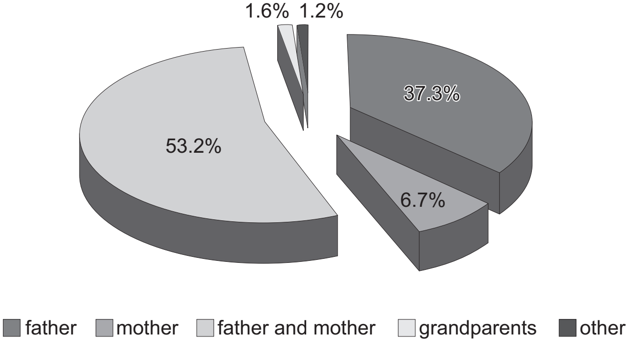


Figure 3. Person earning living expenses mainly

3.3.1.2. Occupation of parents

Regading the occupation of parrents, 97% fathers and 90% mothers were working. 30% fathers and 24% mothers were specialists (Technician/Doctor/Researcher etc), 20.4% father and 11.7% mother worked in industry, 13.6% fathers and 23.1% father were officers/officials (in the governmental organizations), 14.4% father and 12.6% mothers worked in commerce/service sector (Figure 4).

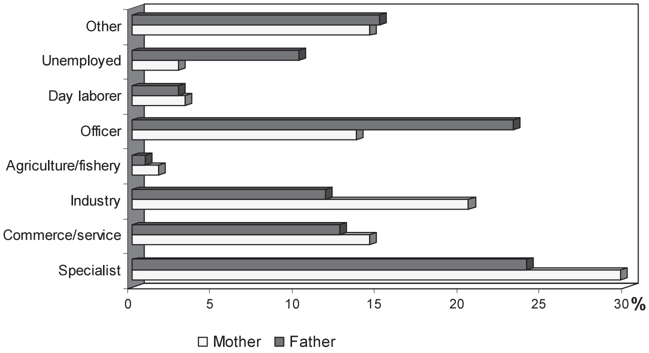


Figure 4. Parents' occupation

3.3.1.3. Household economy

According to parents' self-assessment, 51.8% households' economic status was good (10% good and 41.8% quite good) and 48.2% households' economic status was not good (10% hard and 38.2% a little hard) (Figure 6)

Among households' expenses, highest proportion of parents (94.4%) considered the expense for education and care for the child was too much, following by the cost for food (87%), water and energy (80%), medical bill (68%), and transportation (67%) (table 3).

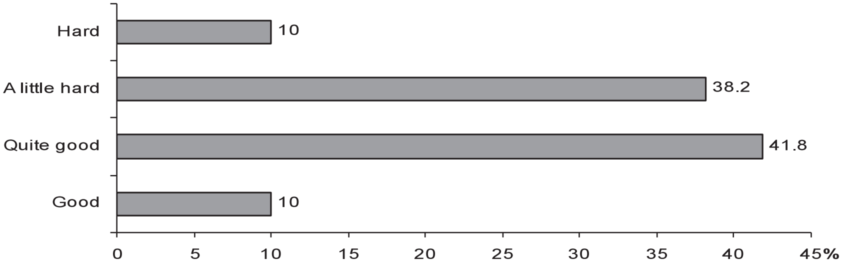


Figure 5. Household economic status

3.3.1.4. Household cost

Table 3. The high expenses in household cost

Household cost	Freq (N)	Percent (%)
Food	220	87.6
Water and energy	201	80.1
Education and care for child	237	94.4
Transportation expense	168	66.9
Medical bill	171	68.1
Cost for housing	34	13.5
Repayment for loan and/or debt	32	12.7

3.3.2. Worries in daily life

3.3.2.1. Worries at present and future

Highest proportion of parents identified spouse (74.5%) and teacher/staff (62%) at institution/school as the confidant that they often consulted or talked about their child's disability, welfare, health care, education, and life. 36.3% identified parents of children with disability as the confidant, 24.5% for child's grandmother, 18.8% for child's grandfather, friend, and colleagues (Figure 6).

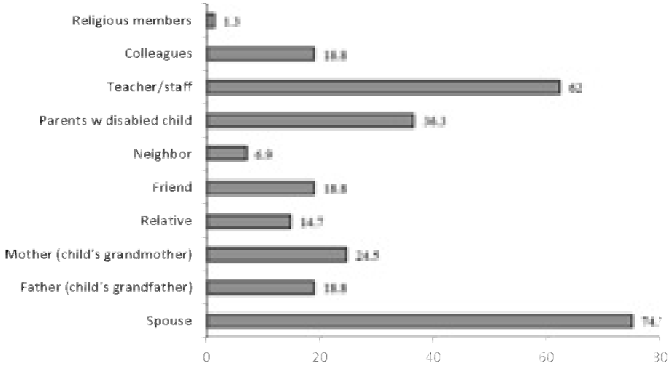


Figure 6: Confidant/consultant for life, health care, education and welfare

At present, Being unable to receive rehabilitation/training (57%), Illness/accident of family (40%), Illness/accident of people earning living expenses (38.2%), Burden with care (37%), No free time (37.8%), Burden with education expenses (31%) were the things that parents worried the most.

For the future, Respondent's old age (how the child live?) (64.6%), Being unable to receive rehabilitation/training (54%), Employment of the child (51.2%), Illness/accident of people earning living expenses (40.9%), Illness/accident of family (36.6%), Marriage of the child (31%) were the things that parents worried the most (Table 4).

Table 4. Worries at present and about the future

Worries	Present		Future	
	Freq	%	Freq	%
Illness/accident of people earning living expenses	97	38.2	104	40.9
Illness/accident of family	86	39.9	93	36.6
Burden with care	94	37.0	72	28.3
Being unable to receive rehabilitation/training	145	57.1	137	53.9
Burden with education expenses	79	31.1	65	25.6
Burden with health expenses	38	15.0	30	11.8
Low income	72	28.3		
Paying off the debts	19	7.5		
No time to be free	96	37.8		
Child's sibling marriage			17	6.7
Employment of the child			130	51.2
Marriage of the child			79	31.1
Respondent's old age (how the child live?)			164	64.6

There were some differences in terms of worried things between parents of children less than 6 and children older than 6. For worries at present, higher proportions of parents of children less than 6 worried about Burden with education expenses (36%) and burden with health care (19%) than parents of children older than 6 (25% and 10%, respectively). The differences were significant with $P < 0.05$) [table 5]. A lower proportion of parents of children less than 6 (33%) worried that they did not have free time compared with parents of children older than 6 year old (46%, $P< 0.05$).

For the future of the child, higher proportions of parents of children older than 6 worried about their old age (78.9%), employment of the child (61.8%) , and marriage of the child (39.3%) than parents of children under 6 (59.5%, 48%, and 27.7%, respectively, with $P< 0.05$).

Table 5. Worries at present, by children's age

Indicators	**Worries at present**		**Worries about future**	
	> 6 ages	**< 6 ages**	**> 6 ages**	**< 6 ages**
Illness/accident of people earning living expenses	46.9	36.9	44.9	41.2
Illness/accident of family	36.3	34	38.2	38.5
Burden with care	42.9	34.6	33.7	27
Being unable to receive rehabilitation/training	53.8	60.8	53.9	58.1
Burden with education expenses	25.3*	35.9	23.6	29.1
Burden with health expenses	9.9*	19.0	11.2	13.5
Low income	28.6	28.8		
Paying off the debts	7.7	7.8		
No time to be free	46.2*	32.9		
Sibling marriage			5.6	8.1
Employment of the child			61.8*	48.0
Marriage of the child			39.3*	27.7
Respondent's old age (how the child live?)			78.9***	59.5

*Note: * P <0.05 ** P <0.01 *** P <0.001*

3.3.2.2. Worries at present and future on daily life and household economic status

There were some differences in terms of worries between parents with good economic status and parents with bad economic status. For worries at present, higher proportions of parents with bad economic status worried about things related to income than parents with good economic status. The worries included burden with education expenses (50% vs. 15%, P<0.001)), burden with health care expenses (22.5% vs. 8.7%, P<0.001)), low income (50.8% vs. 8.7%, P<0.001), and paying off the debt (10.8% vs. 4.7%, P<0.5). Parents with bad economic status also worried more about illness/accident of family than parents with good economic status did (41.7% vs. 28.3%, P<0.05).

Likewise, for future higher proportions of parents with bad economic status worried about burden with health expenses (19.1% vs. 6.4%, P<0.001), burden with education expenses (40.9 vs. 13.6%, P<0.001), burden with care (35.7% vs.

24.8%, P<0.05), and child's employment (61.7% vs. 46.4%, P<0.01) than parents with good economic status.

Table 6. Worries at present by level of economic status

Indicators	Worries at present		Worries about future	
	Good economic	Hard economic	Good economic	Hard economic
Illness/accident of people earning living expenses	37.8	40.8	39.2	47.8
Illness/accident of family	28.3*	41.7	32.0*	46.1
Burden with care	37.0	39.2	24.8*	35.7
Being unable to receive rehabilitation/training	59.8	56.7	53.6	60.9
Burden with education expenses	15.0***	50.0	13.6***	40.9
Burden with health expenses	8.7***	22.5	6.4***	19.1
Low income	8.7***	50.8		
Paying off the debts	4.7*	10.8		
No time to be free	38.9	39.2		
Sibling marriage			8.0	6.1
Employment of the child			46.4**	61.7
Marriage of the child			32.8	32.2
Respondent's old age (how the child live?)			64.8	70.7

*Note: * P <0.05 ** p <0.01 *** p <0.001*

3.3.3. Condition of care

3.3.3.1. Main care giver

Mother is the person mainly responsible for taking care children with disabilities. 75% parents identified mothers as the main care giver for the child with disability. Father was considered as the main care giver by just 7% parents. Grandparents were identified as the care giver by 7.3% parents (Figure 7).

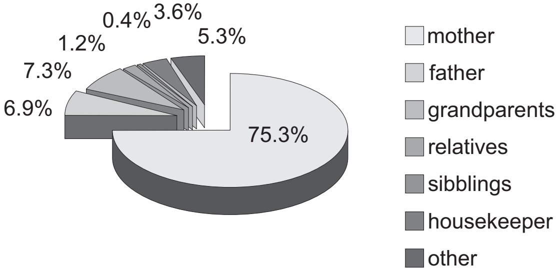


Figure 7. Main care giver

3.3.3.2. Burden and anxiety on caring

Finding a friend (55.3%), Caring of outing (42.3%), Finding an institution available (44.7%), Finding a specialist on education (40%), Caring of feeding (35.8%), Finding a service available (33.7%) were commonly identified as the burden or anxiety on caring for the child by parents (Figure 8).

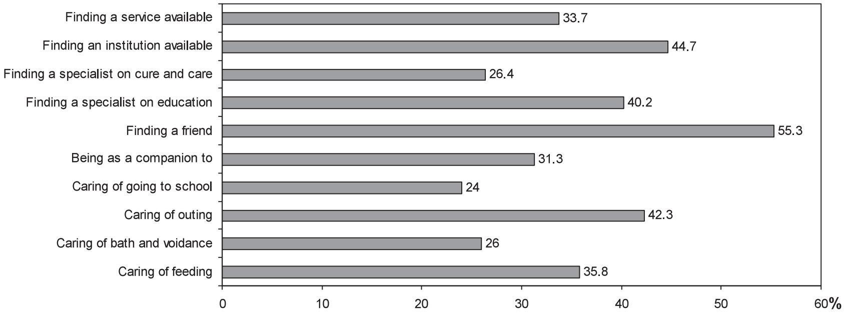


Figure 8: Burden and anxiety on caring for children with disability

3.3.3.3. Caregiver's own burden and anxiety

Having little time on caregiver's side (55%), caregiver's own health (48%), tending to be irritated (37%) were most commonly identified by respondents as the burdens and anxieties of caregiver (Figure 9).

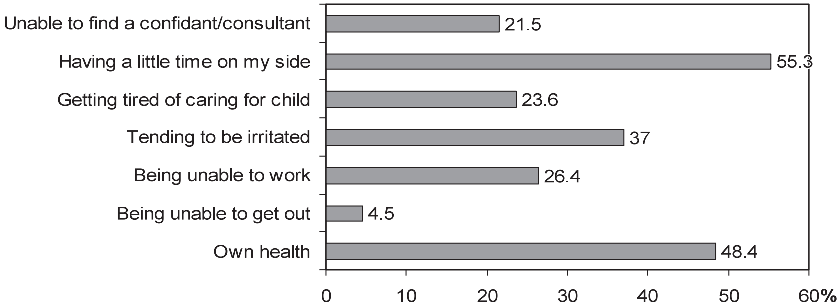


Figure 9. Caregivers' own burden and anxiety

There are some differences in terms of burdens on caring between parents of children older than 6 and parents of children less than 6. Higher proportions of parents with children older than 6 than parent with children less than 6 identified caring of bath and voidance (3.7% vs. 21.7%, P<0.05), caring of outing (50.6% vs. 37.5%, P<0.05), and finding an institution available (52.8% vs. 40.1%, P<0.05) as burdens on caring (Table 7).

Table 7. Burden and anxiety on caring by children's age

Indicators	>6 ages	<6 ages
Caring of feeding	30.6	36.4
Caring of bath and voidance*	33.7	21.7
Caring of outing*	50.6	37.5
Caring of going to school	22.5	25.7
Being as a companion to	31.5	31.6
Finding a friend	60.7	52.6
Finding a specialist on education	39.3	42.1
Finding a specialist on cure and care	24.7	28.3
Finding an institution available *	52.8	40.1
Finding an service available	37.1	31.6

*Note: *P <0.05*

There were some differences in terms of burdens on caring and caregiver's own burdens between parents with good economic status and parents with bad economic status. Higher proportions of parents with good economic status than parents with bad economic status identified caring of feeding (42.7% vs. 29.9%, P<0.05), caring of bath and voidance (33.3% vs. 19.7%, P < 0.05), caring of going to school (30.8% vs. 18.1%, P< 0.05), and being as a companion to (38.5% vs. 25.5%, P<0.05) as burdens on caring for the child.

Regarding caregiver's own burdens, higher proportions of parents with good economic status compared with parents with bad economic status considered being unable to work (39.3% vs. 14.3%, P<0.001), getting tired of caring for child (29.1% vs. 18.3%, P<0.05), unable to find a confidant (23.9% vs. 19.8%, P<0.05), and being unable to get out (7.7% vs. 1.6%, P<0.05) as their own burdens or anxieties (table 11).

Table 8. Caregivers' burden by economic status

Indicators	Household economic status		Total
Burden and anxiety on caring	**Good**	**Hard**	
Caring of feeding*	42.7	29.9	36.1
Caring of bath and voidance*	33.3	19.7	26.2
Caring of outing	47.9	37.8	42.6
Caring of going to school*	30.8	18.1	24.2
Being as a companion to*	38.5	25.5	31.6
Finding a friend	55.6	55.9	55.7
Finding a specialist on education	40.2	40.9	40.6
Finding a specialist on cure and care	31.6	22.0	26.6
Finding an institution available	44.4	44.1	44.3
Finding a service available	35.0	33.1	34.0
Caregivers' own burden and anxiety			
Own health	53.8	45.2	49.4
Being unable to get out*	7.7	1.6	4.5
Being unable to work***	39.3	14.3	26.3
Tending to be irritated	35.9	38.1	37.0
Getting tired of caring for child*	29.1	18.3	23.5
Having little private time	53.0	58.7	56.0
Unable to find a confidant/consultant*	23.9	19.8	21.8

Note: P <0.05 ** P <0.01 *** P <0.001*

3.4. Wishes of support

3.4.1. Economic support/aid, support in daily life and for bringing-up

Regarding economic support, increasing family allowance for child with special needs was the kind of support that parents wished for the most (84%), following by aid for medical bills (45.4%).

In terms of support for daily life, creating more short-stay service for children with special need (67.9%) and Introducing and sending a helper (61.3%) were the two kinds of support that parents wished for the most.

Improving child care center (81%) was the support for bringing up the child that the majority of parents wished. Additionally, 49% parents wanted to see the increasing network of social workers and consultants.

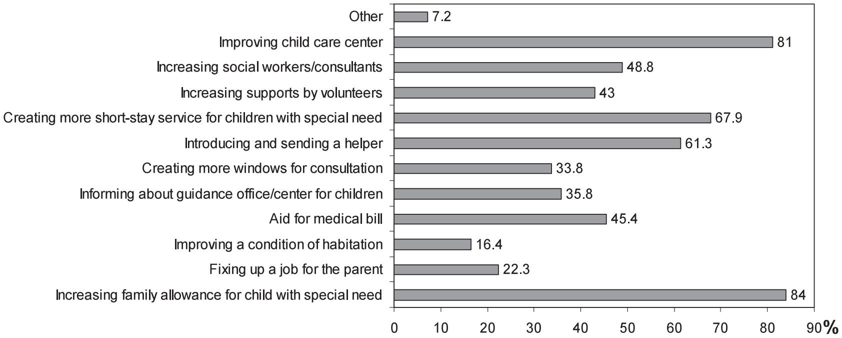


Figure 10. Respondents' wish for supports on economy, daily life and bringing-up.

3.4.2. Primary wish for child's future

For the child's future, the majority (81%) of parents wished their child is becoming independent. This was the only primary wish of parents for the child's future.

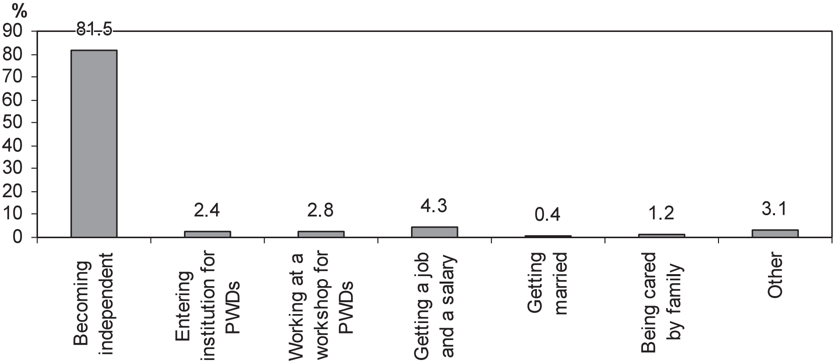


Figure 11. Primary wish for child's future

3.4.3. Relationship between respondent's wishes by factors

There were some differences in terms of the support that parents wished for between parents of children under 6 and parents of children older than 6. Higher proportions of parents with children under 6 wanted to receive support for paying medical bills (49% vs. 30.6%) and to increase social workers/consultants (52.9% vs. 32.7%).

Table 9. Wishes of support in economic, daily life and support for bringing-up by children's age.

Indicators	Child's age		Total
	<6 ages	>6 ages	
Economic support/aid			
Increasing family allowance for child with special need	82.9	87.8	83.9
Fixing up a job for the parent	23.0	20.4	22.5
Improving a condition of rehabilitation	18.2	10.2	16.5
Aid for medical bill*	49.2	30.6	45.3
Support in daily life			
Informing about guidance office/center for children	38.7	25.5	36.1
Creating more windows for consultation	36.6	23.4	34.0
Introducing and sending a helper	59.2	72.3	61.8
Creating more day-care service for children with special need	68.1	66.0	67.6
Support for bringing-up			
Increasing support by volunteers	43.5	40.8	42.9
Increasing social workers/consultants*	52.9	32.7	48.8
Improving child care center	81.2	79.6	80.8

*Note: *P<0.05*

There were some differences in terms of the support that parents wished for between parents with good economic status and parents with bad economic status. In terms of economic support, more parents with bad economic status wished for Fixing up a job for the parent (27.4% parents with bad economic status vs. 17.6% parents with a better economic status, P<0.05), Improving a condition of rehabilitation (23.1% vs. 10.1%, P<0.01), Aid for medical bill (55.6% vs. 34.5%, P<0.01), and Improving child care center (87.9% vs. 75.8%, P<0.05).

Table 10. Wishes of support in economic, daily life and support for bringing-up by household economic status

Indicators	Household economic status		Total
Economic support/aid	**Good**	**Hard**	
Increasing family allowance for child with special need	84.0	85.5	84.7
Fixing up a job for the parent*	17.6	27.4	22.5
Improving a condition of rehabilitation**	10.1	23.1	16.5
Aid for medical bill**	34.5	55.6	44.9
Support in daily life			
Informing about guidance office/center for children	39.3	32.8	36.1
Creating more windows for consultation	36.9	31.0	34.0
Introducing and sending a helper	62.3	61.2	61.8
Creating more day-care service for children with special need	64.8	72.4	68.5
Support for bringing-up			
Increasing support by volunteers	40.3	46.6	43.3
Increasing social workers/consultants	49.2	49.1	49.2
Improving child care center*	75.8	87.9	81.7

*Note:*P<0.05, **P<0.01*

4. DEVELOPMENTAL SUPPORT FOR CHILDREN WITH DISABILITIES

4.1. Detection and diagnosis of child's disability

4.1.1. Medical treatment at a maternity clinic during pregnant (for unusual signs) and situation of child's birth

Among the sample, 19% parents reported unusual signs during pregnancy that needed medical treatment at a maternity clinic and 81% reported there was no unusual sign needed medical care. Regarding the situation at birth of the child, 49% were safe (normal) deliveries and 51% were abnormal deliveries. The abnormal deliveries included Caesarean section (31.3%), asphyxiation (13%), neonatal jaundice (12%), navel string coiled around child's neck (7%), and the child had to be put into infant incubator (9%).

Table 11. Medical treatment at a maternity clinic during pregnancy (for unusual signs) and situation of child's birth

Unusual during pregnant	**Freq (N)**	**Percent (%)**
Yes	46	18.9
No	197	81.1
Situation of Birth		
Safe delivery	121	49.2
Asphyxiation	32	13.0
Navel string coiled around child's neck	17	6.9
Caesarean section	77	31.3
Neonatal jaundice	30	12.2
Being in infant incubator	22	8.9

4.1.2. Time of detection and diagnosis child's disability

Time of detection of the child's disability was the first time when parents suspected that the child had something unusual such as delay or disorder. Time of diagnosis was the time the child disability was identified and confirmed by health professionals.

Time of detection and time of diagnosis was divided into two levels: 1) early level (under 2 years of age) includes time of detection from "Neonate" to "Around 1½ years"; and 2) not-early level (2 years of age and over) includes time of detection from "Around 2 years" to "After the child entering elementary school'.

Among the sample, in only 23.5% of the cases, child's disability was detected early before the child reached the age of 2 and the majority of children were detected with their disability after they were 2 years old.

Likewise, the majority of the children were diagnosed with disability when they were over 2 years old (75.7%); only 24.4% children were diagnosed early before 2 years old (Figure 12).

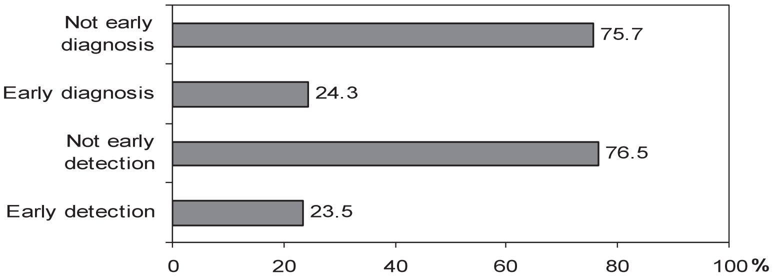


Figure 12. Time of detection and diagnosis child's disbility by early or not early detection and diagnosis.

4.1.3. First person who detected child's "developmental delay" or "disability"

Mother was the first person who recognized the child's developmental delay or disability (65.5% of the cases), following was father (9.9% of the cases). In 4% of the cases, doctors was the first person who suspected the child's disability. Teachers at kindergarten/day nursery were the first person who recognized the child's disability in only 3.6% (table 12).

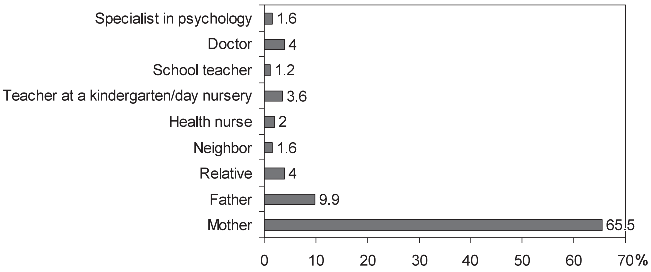


Figure 13. First person who detected child's "developmental delay" or "disability".

4.1.4. Place of first time diagnosing child's "developmental delay" or "disability"

In 56.7% of the cases, parents received the diagnosis for their child's disability at a hospital or medical center. 7.5% parents were informed their child's disability at a health care center, and 8% at kindergartens/day nurseries (table 18).

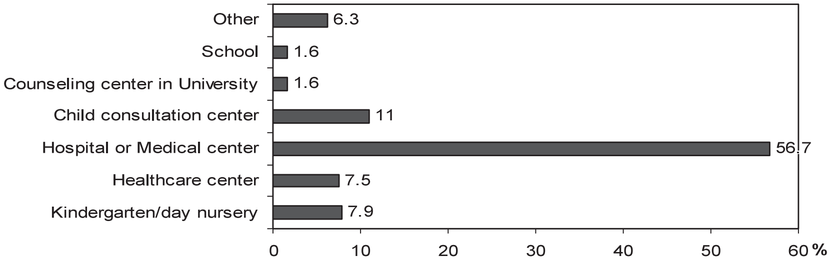


Figure 14. Place of first time diagnosing child's "developmental delay" or "disability"

4.1.5. Parent's feeling when they knew their child's disability

The feeling and reaction of parents right after receiving the diagnosis for child's disability was complex. 51.6% parents reported they were shocked, 73.2% were anxious for the future, 72.8% thought about how to make the child a normal one, 76% thought about the way that make the child recover. Only 10% said they were unable to accept the diagnosis.

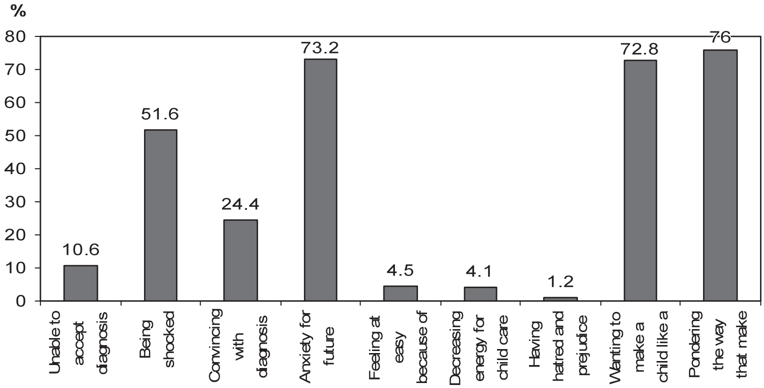


Figure 15. Parent’s feeling when they knew their child’s disability.

4.1.6. Parents’ wishes for hospital and special institution

When asked about what they wanted hospitals and special institutions to do more for their children, the majority of parents expressed that they wanted more instruction for parents to do for the child (77%), more support for parents (69%), more special doctors (41%), and 41% wanted to have more institutions dealing with disabilities.

Table 12 . Parents’ wishes for hospital and special institution

Parents’ wishes	Freq (N)	Percent (%)
Increase special doctors	101	41.1
Support for parents	171	69.5
Increase institutions which can deal with disability	100	40.7
Uniform criteria of diagnosis	69	28.0
Make explanations much easier	70	28.5
Make enough time for medical examination and counseling	88	35.8
Telling what parents can do for the child	190	77.2
No expectation	5	2.0

4.1.7. Relationship between time of detection/diagnosis and other factors

There were some differences in terms of being detected or diagnosed early in relation with type of disability, the level of support child needed, and household's economic status.

Regarding type of disability, a lower proportion of children with autism (17%) was diagnosed than children with other developmental disorders (27%).

In terms of level of support, a higher proportions of children who needed support totally (40%) and partially (20%) were detected early than children who did not need support for their basic activities (5.6%).

Regarding the household economic status, a higher proportion of children from families with hard economic status were detected and diagnosed early compared with children from families with good economic status.

Table 13. Relationship between time of detection/diagnosis and other factors

Indicators	Detection		Diagnosis	
	Not early	Early	Not early	Early
Gender				
Male	75.7	24.3	76.3	23.7
Female	78.3	21.7	72.1	27.9
Age				
<6	76.8	23.2	75.9	24.1
>6	76.0	24.0	73.9	26.1
Communication ability				
Good	73.1	26.9	69.2	30.8
Bad	77.7	22.3	77.4	22.6
Type of disability				
Autism	81.9	18.1	82.8*	17.2
Others	74.5	25.5	72.6	27.4
Support child needed				
Totally	59.7***	40.3	57.8	42.2
Partially	79.7	20.3	79.0	21.0
Not needed	94.4	5.6	94.4	5.6
Household economy status				
Good	82.9**	17.1	84.0**	16.0
Bad	68.9	31.1	66.4	33.6

*Note:*P<0.05, **P<0.01, ***P<0.001.*

Among types of disabilities, physical disability, behavioral problems (the visible and easily to recognize) were the ones that were detected and diagnosed earlier than other types of disabilities (Table 14).

Table 14. Types of disability and detection/diagnosis.

Types of disability	**Detection**		**Diagnosis**	
	Not early	**Early**	**Not early**	**Early**
Intellectual disability	75.0	25.0	71.7	28.3
Physical disability	58.3	41.7	54.5	45.5
Language disorder	79.7	20.3	76.1	23.9
Developmental disorder (autism or Asperger's syndrome)	81.9	18.1	82.8	17.2
Developmental disorder (ADHD and/or LD)	75.0	25.0	90.9	9.1
Behavioral problem	60.0	40.0	60.0	40.0

4.1.8. Logistic Regression results associated with early detection vs Not early detection and Early diagnosis and Not early diagnosis.

In order to explore factors associated with being detected or diagnosed early, logistic regression was run with being detected (or diagnosed) early as dependent variables and gender, age, type of child's disability, household economic status, child communication ability, and support needed as independent variables. Two models were run separately for detection and diagnosis.

Results from logistic regression indicated several factors associated with time of detection and time of diagnosis (table 23). Children with other types of disability rather than autism were 2 times more likely to be diagnosed early than children with autism. Children from families with bad economic status were 2 times and 3 times more likely than children from good economic families to be detected and diagnosed early, respectively. Children needed support totally and partially were 24 and 7 times more likely than children who did not need support to be detected early, respectively. Likewise, children needed support totally and partially were 41 times and 11 times more likely than the ones who did not need support to be diagnosed early, respectively.

Table 15. Logistic Regression results associated with early detection vs Not early detection and Early diagnosis and Not early diagnosis.

Independent variables	**Early detection vs Not early detection**		**Early diagnosis vs Not early diagnosis**	
N=254	**Odds Ratio**	**95% CI**	**Odds Ratio**	**95% CI**
Gender				
Female (ref)	1.00		1.00	
Male	2.28	0.89, 5.86	1.49	0.61, 3.70
Age categorized				
<6 ages (ref)	1.00		1.00	
>6 ages	1.05	0.48, 2.27	1.16	0.52, 2.57
Types of child's disability				
Autism or Asperser (ref)	1.00		1.00	
Others	1.70	0.88, 3.24	2.14*	1.09, 4.19
Household economic status				
Good (ref)	1.00		1.00	
Bad	2.28**	1.22, 4.28	3.01***	1.58, 5.74
Child's communication ability				
Bad (ref)	1.00		1.00	
Good	3.00*	1.00, 8.97	3.82*	1.27, 11.48
Level of support needed				
No support needed	1.00		1.00	
Totally	24.56***	4.42, 136.4	41.01***	6.59, 255.05
Partially	7.53**	1.51, 37.5	11.09**	2.06, 59.5

*Note:*P<0.05, **P<0.01, ***P<0.001.*

4.2. Early intervention and early education for child

4.2.1. Times from detection, diagnosis, to intervention

Time between first recognized, diagnosis, and intervention was close. About 50% children received diagnosis and intervention at 2-<3 years of age. 20% diagnosed and received intervention at 1-<2 years old and 20% at 3-<4 years old. Right after receiving diagnosis, the majority of parents sought for intervention/education for the child.

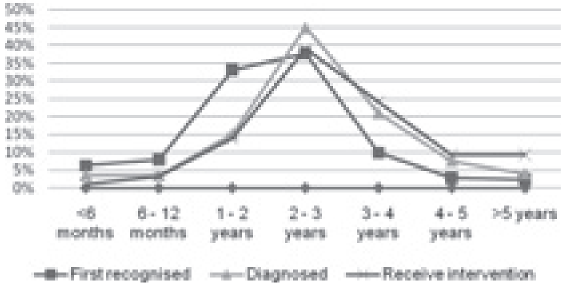


Figure 15. Time periods: first recognized, diagnosed and receive intervention.

4.2.2. Place, types of early intervention

84% of children with disability received early intervention. 15% of them received intervention from hospitals, 25.6% from private training institutions, 11.6% from special kindergartens, 11.6% from special classes in ordinary kindergartens, and 11.2% received interventions from counseling centers. 65% children received both group therapy and individual therapy, 27% received individual therapy only, and 7.5% received group therapy only (table 16).

Table 16. Receive, place, types of early intervention/early education program

Early intervention	Freq (N)	Percent (%)
Yes	213	83.9
No	33	13.0
Place providing early intervention/early education program		
Free public training institution	6	2.8
Paid public training institution	13	6.0
Private training institution	55	25.6
Regular class of kindergarten	15	7
Special class of kindergarten	25	11.6
Special kindergarten	25	11.6
Hospital	32	14.9
Counseling/guidance center	24	11.2
Home	5	2.3
Other	15	7.0
Therapy types		
Group therapy	16	7.5
Individual therapy	58	27.1
Both	140	65.4

4.2.3. Types of early intervention program

Regarding the type of therapy in early intervention, 85.6% children received speech therapy, 68% received training for daily activities, 64% for behavioral therapy, 54% play therapy, 48% sensory integrated therapy, and 30% received music therapy (Figure 16)

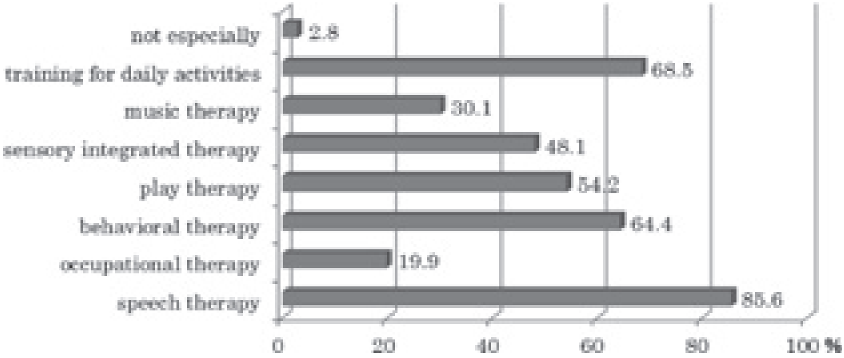


Figure 16. Types of early intervention

4.2.4. Time receiving early intervention program

Forty-five percent children with developmental disorder received intervention when they were less than 3 years old (11.8% at 1-2 years old, and 33.1% at 2-3 years old). 20.5% received intervention when they were 2-3 years old and about 16% received intervention when they were over 4 years old (figure 17).

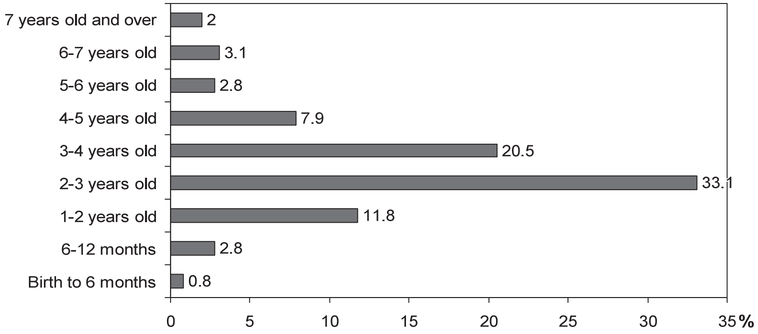


Figure 17: First time received intervention/early education program.

Household economic status was not significantly associated with the time children received intervention (table 17).

Table 17. First time received early intervention BY economy situation

Ages	Household economic status		Total
	Good	Hard	
Under 6 months	0.9	1.0	0.9
6-12 months	2.8	3.9	3.3
1-2 years old	10.1	16.5	13.2
2-3 years old	40.4	38.8	39.6
3-4 years old	25.7	22.3	24.1
4-5 years old	11.9	6.8	9.4
5-6 years old	3.7	2.9	3.3
6-7 years old	2.8	4.9	3.8
7 years old and over	1.8	2.9	2.4

4.2.5. Burden for receiving early intervention or early education programs

Three main factors that parents considered as burdens (or obstacles) in receiving early intervention for their children included time (59.3%), finance (45.9%), arrangement of living (life) (43.1%), and man power (29.2%).

Parents with bad economic status were more likely to consider finance as burden of receiving intervention. Additionally, a higher proportion of parents with good economic status (19%) considered a little burden when receiving intervention for their children than parents with bad economic status (9%).

Table 18: Burdens in receiving intervention by household's economic status

Burdens	Good economic	Hard economic	Total
Time	56.0	63.0	59.3
Finance***	26.6	67.0	45.9
Man Power	25.7	33.0	29.2
Living arrangement	42.2	44.0	43.1
Little or no burden*	19.3	9.0	14.4

*Note: * P <0.05 *** P <0.001*

4.2.6. Level of satisfaction and intervention/education programs

Regarding the level of satisfaction with the intervention/education programs, 50% parents were satisfied, 24% were much satisfied, 26% were less satisfied, and only 0.5% were not satisfied.

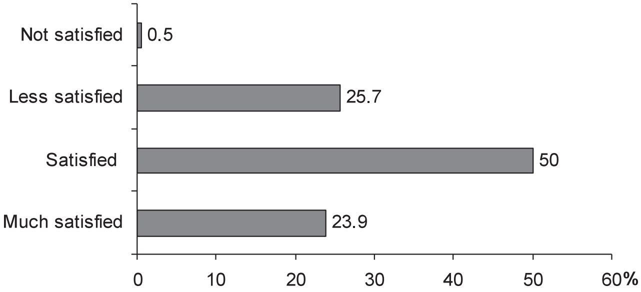


Figure 18. Level of satisfaction with interventions

4.2.7. Person that respondents often consult about child's developmental support

For child's developmental support, specialists at counseling centers (22.8%), teacher of school (22.4%), psychological experts (18.9%), and doctors (11%) were people with whom parents often consulted.

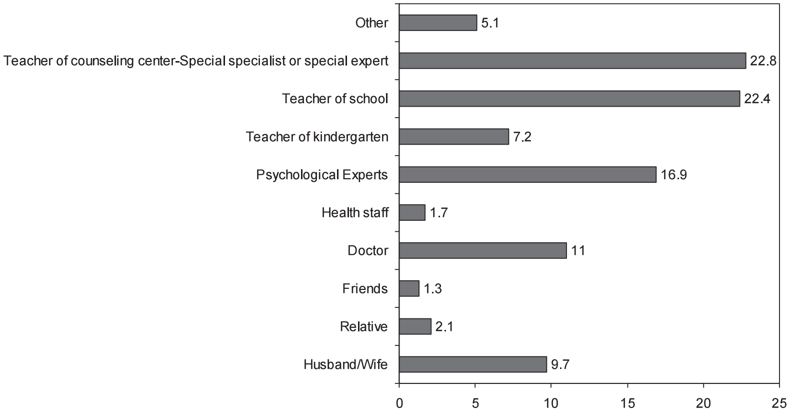


Figure 19. Person (including specialist) that respondents often consult about child's developmental support

Among types of support that parents wanted to receive from intervention programs, Support for learning (71%), Development support for child (68%), Wish for friends and playmate (64.6%), Support for child's disability (63%), Enrichment of staff with special knowledge (56%) were the most commonly indicated by parents.

There were differences in terms of support wanted to receive from the intervention programs by parents with bad economic status and parents with good economic status. More parents with bad economic status wanted to have support for decreasing burden of family, Financial support , Development support for child (P <0.001).

Table 19. Type of support respondents need by household economic status

Indicators	Household economy		Total
	Good	Hard	
Types of support respondents wish			
Support for child's disability	65.1	60.7	63.0
Development support for child***	57.9	79.5	68.3
Financial support***	24.6	54.7	39.1
Support for learning	69.0	73.5	71.2
Wish for friends and playmate	62.7	66.7	64.6
Support for decreasing burden of family***	15.1	35.9	25.1
Enrichment of education program	50.0	41.0	45.7
Enrichment of staff with special knowledge	61.1	50.4	56.0
Enrichment of public officer	6.3	11.1	8.6

Note: p <0.05 ** p <0.01 *** p <0.001*

5. CASE STUDY

Case study for Parental Feeling on the process of acceptance of Information about ASD and Parental Needs.

The aims of this case study is to clarify the needs for children with ASD and their family, the Parental feeling on the acceptance of Information about ASD

The subjects were the parents of 3 children with High functioning Autism or Asperger syndrome, and the children belongs to regular class at elementary school and primary school at present.

The case study focused on:

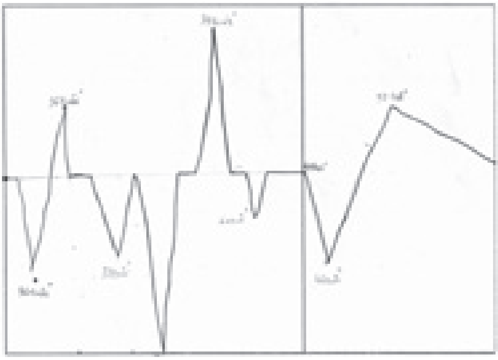
- The process of early detection, diagnosis, and early intervention
- The difficulties parents experienced, and the needs of support parents wished to receive
- The supports which parents were helped
- The needs for medical treatment, early intervention, education
- The way parents see the children's future

5.1. Case A

Sex: Male

Age: 5 years and 6 months

5.1.1. What was told at LIM?



5.1.2. Process of Suspicion → Detection → Intervention → Diagnosis

	Age	Status
Suspicion	1 years old	- Children didn't make a sound like "ba" or "pa"
		- Children didn't often see mother'face when she feeding
Parents' Suspicion	1-2 years	- Delay in language. Often be axious. The difficulties in developing in sleep rhythm. Always hold the same pillow. Parents was consuting that the child don't have ASD traits Child became hyper active, and became not to be responded to others
Suspicion	2 years & 3 months	Children have trouble in the Kindergaten, he couldn't interact with peers and teachers, make a loud sound and cry very often. Over anxiety. Parent was tell that should take the child to check about ASD.
Detection	2 years and 3 months	Parents decided to Doctor at Paediatric Hospital. Docter suspected see the Autism .
Counseling	2 years and 3 months	Docters adviced parents to take Intervention program for Child
Early Intervention	2 years and 3 months	Children started to join the Hope centre all day
Diagnosis	3 years	The child was diagnosed as Autism with hyper active.

5.1.3. The needs of support

Period	Status	Needs support
Detection	○ Parents are told the problem of the child, but there were not any support for the child nor the parents. ○ There were not teachers have knowlegde and skill to support child and parents at kindergaten	* The system to introduce about the counseling and intervention soon after the suspicion of parents * The support of parent * The specialist, teachers who have knowledge about ASD, and can help parents go to counseling or hospital
Intervention → Diagnosis	○ Parents did not want to go to counseling and diagnosis because afraid of Autism label form their parents in laws. But all family have stressful feeling so they took the chidren to see the docter. ○ Parents started to think about Autism, by watching children during intervention.	* The counseling of parents and other members in family. * To help them understand child's behavior,
Entrance of normal Preschool	○ Before entering normal preschool, parents could not have enough consultation.	* To counseling for parents about chosing approciately school for child.

5.1.4. The support which parents were helped and wished

Fiels	Wishes
Docters	- Docter help to determind children's problems, guiding to use the medicine and treatment.
Teachers	Teachers can sympathise with children, support parents to teach for child at home.
Family and friends	Support for parent to take children to special centre. Support financing
Media system	- Help parents more understand about the ASD and children'behaviours.

5.1.5. The wishes for the future

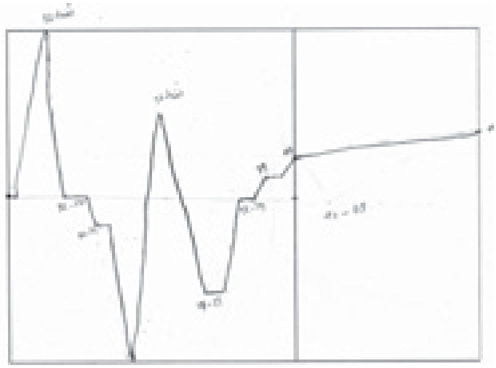
- Parents worry if their child have enough skills to go to school and which Primary school will acceptance children.
- They want children can go to the normal school, received the assement before to enter primary school.
- They wish their child will be better and can get a job, to become independent and get married

5.2. Case B

Sex: Male

Age: 8 years old

5.2.1. What was told at LIM?



5.3.2. Process of Suspicion → Detection → Intervention → Diagnosis

	Age	Presentation
Suspicion	1 years old	The child din't say a word. He couldn't not make distinction father and mother.
Suspicion	2 years old	Didn't say any word expcept two words "cho ve", not exciting to the objects and person. Keen on to wacthing television, specially advertising program.
	The first half of the 2nd years old	Often cry, Not communicating with other Children, difficulties in social interaction.
	Before 3 years old	Sing a lot of Chinese, English, Vietnamese songs. But never use language to communication, echolalic speech, don't express emotions with parents and others.
Detection	3 years old and 6 months	Mother took the child to see Doctor at Paediatric Hospital and was told the suspicion of Autism
Counseling	6 months 3 years old	Consulting about child with Psychological and Docter at Hospital
Diagnosis intervention	6 months 3 years old	Being diagnosed High functioning Autism Start to receive intervention at special education centre.

5.2.3. The needs of support

Period	Status	Needs support
Suspicion → Detection	○ Parents have suspicion but didn't receive any support. The child was suffuring the isolating of neighbours. The husband and others members of family thought that is mother's fault The teachers didn't have skill to work with children	* Early detection according to the suspicion of parents * Counseling for people to understand about children with special need
Intervention and Diagnosis	○ Docter's counseling to joint the special centre but parents didn't have enough knowlegde to decide which shool is good for children.	* Counseling about the school for parents.
Enter school	○ Parents didn't have information about the primary school. They make the decision by them self. The teachers don't have special skill	To transit the support of elementary school to Secondary School

5.2.4. The support which parents were helped and wished

Fiels	Wishes
Doctors	Docter help to determind children's problems, guiding the way to take care for children.
Psychological and experts	Counseling and providing the information about ASD for parents
Teachers	Come to teach child at home, counseling for parents to interact with children and chose the approxiate school for child. Help child have skill to go to inclusive school

5.2.5. The wishes for the future

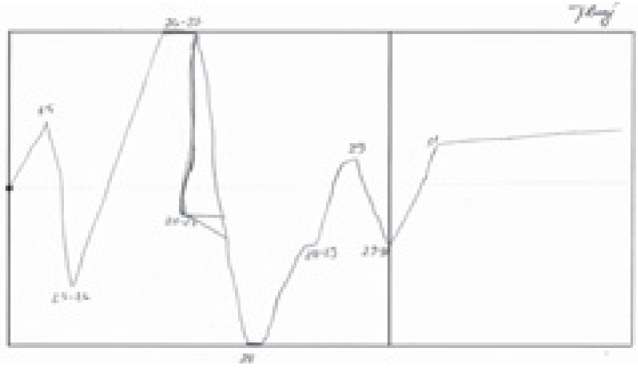
- Parents worry if their child can joint to the normal education systerm
- They wish their child will be better and can get a job, to become independent and get married.

5.3. Case C

Sex: Male

Age: 4 years old

5.3.1. What was told at LIM?



5.3.2. Process of Suspicion → Detection → Intervention → Diagnosis

	Age	Presentation
Suspicion	1and 6 months years old	Language delay.He have troubles at kindergarten, not communicate with otherchildren
Suspicion	2 years old	He easy to get angry. There wasn't not improving about the language.
	Before 3 years old	Parents recognize that the children have lower cognitive than his younger sister (1 years old and six months).
Detection	3 years	Mother took the child to see Doctor at ABCD centre was told that suspicion of Autism
Counseling	3 years old and 2 months	Parents go to Consulting ats centers. Researching on internet about ASD. Contact with friends and others parents of ASD children.
Diagnosis intervention	3 years old and 5 months	Being diagnosed Autism and Start to receive intervention at special education centre. (TDCSE)

5.3.3. The needs of support

Period	Status	Needs support
Suspicion → Detection	○ Parents have suspicion and searching on internet and counseling with friends but don't think about ASD. • Members of Husband's family thought that is mother's fault • The teachers in kindergarten didn't have skill to work with children	Systerm of Early detection according to the suspicion of parents. More experts and teachers have knowledge to counseling for parents. * Counseling for people to understand about children with special need
Intervention and Diagnosis	○ Docter's counseling to joint the special centre. Parents' friends counseling about the school but parents didn't have enough knowlegde to decide which shool is good for children.	* Counseling about the school for parents.

5.3.4. The support which parents were helped and wished

Fiels	wishes
Docters	Docter help to determind children's problems, guiding the way to take care for children.
Psychological and experts	Counseling and providing the information about ASD for parents
Teachers	Come to teach child at home, counseling for parents to interact with children and chose the approxiate school for child. Help child have skill to go to inclusive school
Friends	Sharing informations to help parent pass the sock and help to find the good Intervention centre
Internet	To understand about ASD and communicate woth others parents have ASD children also.

5.3.5. The wishes for the future

- Parents worry if their child will continue improving in the next steps. If they did the best thing for their children or not. Can the child go to normal school and made friends with peers.

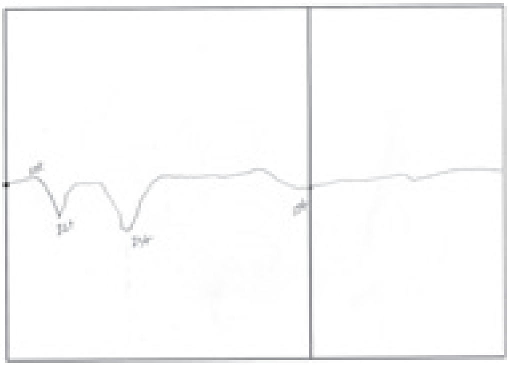
- They are not yet know what will be their children's future.

5.4. Findings from case study

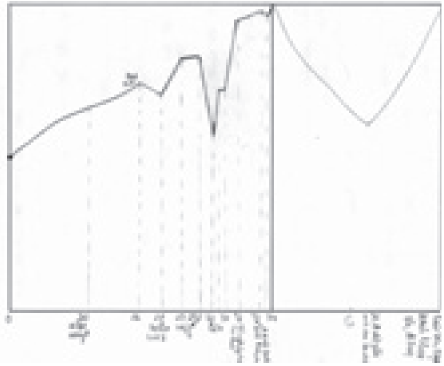
5.4.1. LIM results

- There tend to be common way that the time of diagnosis was the lowest point in their life, then rises at present or the future ⇒ <u>same results as the previous research on LIM</u> (Same as Japanese)
- Mostly, the time of diagnosis is described as the bottom of the life, regardless of the time of suspicion or detection or starting intervention ⇒ <u>same results as survey in Viet nam.</u> (<u>Same as Japanese</u>)
- According to case A,B we found that the shock will not last longer because after diagnosis the children have medicine treatment and joint to the intervention at special centre and they have some improving.But after that parents will be hopeless and disappoint because they found that the children will improve verry slowly. (Quite different from Japanese.)

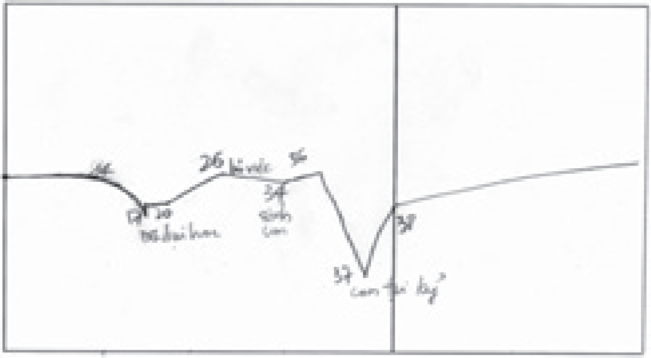
Case D.



Case E.



Case F.



5.4.2. Semi-structured interview result

- Diagnosis

- Children’s disorder will not be cured ⇒ Parents think strongly they must do something for them(<u>Case A, B, C</u>) (same with Japanese)
- Just like anothers deases, if have right medicine and treatment the children will be normal.(Parent don’t understand about ASD- <u>Case D</u>-difference with Japanese)

- Parents feels some kinds of duty they have to bring up children with ASD, so that they have risk for parents shopping for intervention, if there are not enough support (<u>Case A</u>) (same with Japanese)
- The needs to understand the feeling of the parents, self-isolated, pressure, self-denial, and the needs for support of parents (same with Japanese)

5.4.3. The process of suspicion/detection/diagnosis/intervention

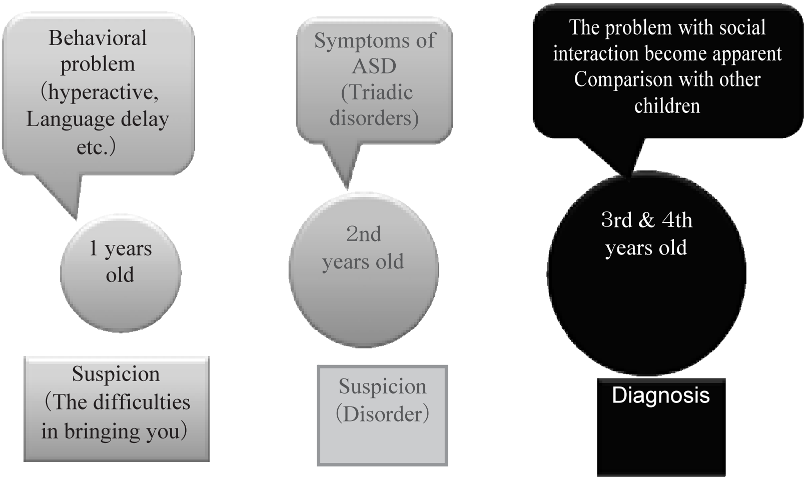
- The time of diagnosis was 2,5-4 years old at each 3 cases (need to determind the concept of Diagnosis in Viet Nam)
- The difference in process of Suspicion → Detection, Diagnosis → Intervention

\- Suspicion → Detection → Intervention → Diagnosis: <u>Case A</u>.

\- Suspicion → Detection → Diagnosis-Early Intervention: <u>Case B, C</u>

The growing suspicion

The suspicion become deep gradually (the same with Japanese but difference is the time to start to suspect: in Vietnam often at 1 years old).



5.4.4. The difficulties parents experienced

- Parents get anxiety because of time lag

- Suspicioun → Detection

Parents need the support from the experts when they suspected about the develoment of the child at the same time co connect with parents to support for them.(Case A, B, C)

- Detection → Diagnosis

The docters should give to parents the consultant to help them understand children and help them to cordinate the supporting sources for the child's needs when they received the diagnosis. (Case A, B,C)

- Diagnosis - Intervention

Need the media system and Docter and experts's consultant for parents about the Early intervention centre and specail schools

- Time of Transition

Need the transition system and continuously supporting between grades. (Case A)

5.4.5. The supports which helped parents

The role of specialists at the centres: To understand about ASD

The role of teachers:

- Support for child at home and centre, counseling for parents to chose the school.

- The role of Psychological
- Counseling spychological
- The role of Doctor: Determind the ASD and counseling to treatment and intervention for parents
- The role of Family, friends: Support in finacial, take caring the children,and sympthize.

5.4.6. The need for medical treament, early intervention, education

- Medical treament:

- Enrich docters have knowledge about ASD to guiding for parents in medicine using.
- Enrich treatment centre for ASD children.

- Early intervention, education:

- Enrich the school systerm for ASD children.
- More teachers to support for children at home and at school.
- Enrich experts to counseling for parents to understand about ASD.

5.4.7. The ways parents see the children's future

- Some parents hope that the children will be independent, have job and get married (Case A, B)
- Some parents don't think about future, they just think about the present how to help children to be normal and can go to school.(Case C, D, E)

6. CONCLUSIONS

Almost all children who involved in this research were under 6 years old (80%) and they were diagnosed developmental disorder such as: ASD, asperser, ADHD, and language delay.

More than a half of them (59%) needed partially help for basic activities and especially difficulty in communication. Children under 6 needed more support than children older 6 (38% and 8,4%).

Almost all parents of the children were working and had a good job, but there was a significant difference in terms of being a person mainly earning expenses for the family between father and mother (37% fathers and 6,7% mothers). The income of family comes mainly from father. General speaking, 51,8% parents in this research felt that their economic status are good. This might affect the way they spent money for their child and the services they chose for their child. However, parents from low-income family expected to get a better job to be able to cover a lot of expenses for the family with a disable child.

Regarding the expenses in household cost: Family with a disable child faced the high cost of many items, especially for education and care for the child; food; water and energy; medical bill; and transportation. This makes the family with low-income became harder.

The majority of children were diagnosed with developmental disorders late. Among the sample, in only 23.5% of the cases, child's disability was detected and diagnosed (24.4%) early before the child reached the age of 2 and the majority of children were detected and diagnosed with their disability after they were 2 years old.

The good thing is that as soon as the child was dignosed, their parent took some early intervention program intensively for the child. Individual intervention is kind of early intervention program what was chosen by almost all perents.

The needs of families with disable children were related to caring for their child. The parents had a lot of worries about many matters, such as information relating to ASD, ADHD and language development; where they can reach for help; where they can get an appropriate service for their child; how to predict the development of their child.

The need of support of families with disable child: Parents expressed their desires to get supports relating to:

- Economic support: social welfare system should pay attention/consider to support financially for the CwD.
- Developing and improving the services/centers/institution/schools for the CwD.
- Providing accessible information relating to ASD, ADHD, specialists and organizations/centers with whom and where they can get help/consultancy.
- Developing treatment/intervention/consultation programs as well as capacity building of professionals, social workers, volunteer, who can help/work hand by hand with the parents in caring, sharing and educating the child.

Parent's wish for the CwD's future: high percentage of parents (81%) wish their child becoming independent in their future life. Some parents wish if their child would have a job in particular work-place for PwD in the future.

7. RECOMMENDATIONS

It is needed to develop a comprehensive system of heath care, intervention, information and education and child's welfare for children with developmental disorder/ASD.

Quantity and quality of the existing services should be increased to meet the needs of new categories of disability as ASD, ADHD. This can be done by training for professionals, teachers, social workers; and improving policy and cooperation among different sectors (professions and finance).

In terms of training: to create more professional training focusing on in-depth areas such as: physical therapy (PT), occupation therapy (OT), sensory therapy, speech therapy, Psychiatric, Psychologist...ect. The early intervention's disciplinary should be adapted so that it can work well on each child. Teachers also should pay more attention on recognizing and helping children with ASD.

In terms of heath care: screening programs including early detection and early identification should be improved and worked closely with special education.

In terms of child welfare, child care, protection and prevention: Governmental sectors should develop more guidelines for different groups of children in difficult circumstances and focusing on CwD about respite day-care service, save children center, open social house to share/decreasing burden with their parents.

In terms of information accessible: Public mass-media system should have more programs/channels to provide necessary information regarding prevention, recognition of children at risk. Also parents of CwD should be able to access information to get help/service/professionals/teachers for their child. Awareness of and attitude of people on existing CwD should be increased.

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Reports and Presentations Made Thus Far Pertaining to This Report

Maeda, A. (2010) "Research into children with autism spectrum disorder and their families in Japan- Comparing ʻAutism spectrum disorder：ASD' and ʻMental Retardation：MR' at the 5th Seminar on Developing Treatment Education Programs for Children with Developmental Disorders in East Asia.

Arai, Y. and Araki, M. (2010) “Case study on needs for children with ASD and their families” at the 5th Seminar on the Development of Therapeutic Education Programs for Children with Developmental Disorders in East Asia.

Araki, M. and Arai, Y. (2010) “Case study on needs for children with ASD and their families” at the 6th Seminar on the Development of Therapeutic Education Programs for Children with Developmental Disorders in East Asia.