

# ORIGINAL ARTICLE

# A Preliminary Study of the Diagnosis Process of Children With Disabilities in Malaysia

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## ABSTRACT

**Introduction:** This study surveyed the experience of Malaysian families of children with disabilities during their children's diagnostic process and the support and information they received after the diagnosis. **Methods:** A quantitative research method was employed where data was collected by utilizing a set of questionnaires and analysed using the Statistical Package for Social Science (SPSS). A total of 216 parents of children with disabilities participated by providing responses to questions about the assessment and diagnosis process that their children went through and the services and assistance which were made available to them after these processes. **Results:** The results showed that most of the parents had good impressions of the services rendered to their children during the assessment and diagnosis processes. However, several issues were brought to attention such as issues in early identification of children with disabilities, the diagnostic process itself and support for parents and children post diagnosis. **Conclusion:** Further research is needed to provide a clearer understanding of the issues highlighted in this study. Early recommendations to overcome these issues were put forward; that is to look for alternatives in order to ensure better diagnosis strategies and parent support for the benefit of children with disabilities in this country in the long run.

**Key words :** Children with disabilities, Parents' experiences, Diagnosis processes

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## INTRODUCTION

Early identification and diagnosis of children with disabilities is important in making a prompt intervention to support children and their families as it will significantly influence life of the children and the family in long term time (1,2). Therefore, the issues such as service provisions, school placements etc. are tackled before they become more ingrained problems (3). Early intervention has been shown to significantly improve children's development progress.

Previous findings have identified many barriers for the delayed diagnosis. For instance, in children with autism

spectrum disorder (ASD), the diagnosis is difficult for a multitude of reasons including inconsistency in individual symptoms, overlap with other developmental disorders, limited understanding of cultural differences experienced by the patient's family and lack of trust in the health care provider (4,5). Mothers from low and middle income countries also reported that negative experiences with paediatrician-mother interactions during the diagnostic process may induce their children being diagnosed with ASD at delayed (preschool) age (6). Other developmental disabilities, such as learning disabilities, can also be hard to diagnose, because there is no definitive list of symptoms that fit every child. Also, there are possibilities that many children try to hide the problem. For instance, parents may not notice anything more obvious than frequent complaints about homework or refusal to go to school (7,8).

Delays in obtaining a diagnosis may result in low levels

of parental satisfaction and parents' well-being and can impede effective support or intervention programs (9). Most parents needed information at the time of diagnosis, with information about educating the children highest on the list (10). Early identification of developmental disabilities and appropriate management can positively alter the child's developmental trajectory (11).

A local research (12) highlighted the lack of standardized and culturally sensitive measurements and the limited number of professionals with specialized training to deal with identification of children with specific learning disabilities in Malaysia. Apart from that, providing support for parents of children at the early stage of diagnosis is crucial as a previous research described that parents caring for a younger age group of children with ASD showed higher levels of depressive symptoms compared to parents of older age group (13). Besides, professional support during pre and post-diagnostic processes were considered as one of the important predictors in parental satisfaction with the overall process of diagnosis (1,14).

## MATERIALS AND METHODS

### Study Sample

Respondents of this study were 216 parents of children with disabilities from three different states in Malaysia recruited through a convenient sampling. Most respondents (171) were from Selangor; 30 respondents were from Pahang and 15 respondents were from Terengganu. Since this was a pilot study, a convenience sample was used as it allowed the researcher to obtain elementary data and trends regarding the subject matter in this study.

### Instruments

The questionnaires used in this study were developed through reviews of previous articles on the topic. Adapting an existing questionnaire for use in this study was not feasible as the issues faced by parents in Malaysia were unique to this country. For content validity, the questionnaire was examined by a special education expert and two parents of children with disabilities. With their feedback, some items in the questionnaires were improved. Next, face validity was determined by inviting another special education expert to evaluate the second draft of the questionnaire.

This questionnaire was divided into two parts: Part A and Part B. Part A consisted of two sections; the first section contained items to gather demographic information of the parents or guardians while the second section contained items to gather demographic information of the children themselves. Items in these sections included gender, age, race, religion, and relationship with the child, income, type of disability, and educational placement of the child. Part B contained items on the assessment and diagnosis process that their children went through

**Table I Demographic Information of Parents / Guardians**

Item		<i>n</i>	<i>f</i> (%)
Gender	Male	104	48.1
	Female	108	50.0
	Not available	4	1.9
Age	20 years and under	2	0.9
	20 to 30 years	5	2.3
	31 to 40 years	70	32.4
	41 to 50 years	69	31.9
	51 to 60 years	49	22.7
	60 years and above	15	6.9
	Not available	6	2.8
Ethnicity	Malay	146	67.6
	Chinese	56	25.9
	Indian	9	4.2
	Others	5	2.3
Relationship with child	Mother / Father	206	95.4
	Grandfather / grand-mother	3	1.4
	Relative	1	0.5
	Sibling	4	1.9
	Not available	2	0.9
Level of education	Middle Secondary Assessment	58	26.9
	Malaysia	75	34.7
	Certificate of Education		
	Diploma	23	10.6
	Bachelor's Degree	22	10.2
	Masters' / PhD	4	1.9
	No formal education	21	9.7
	Primary	3	1.4
	Not available	10	4.6
Monthly	RM1000 and below	89	41.2
Income	RM1000 to RM2000	49	22.70
	RM2000 to RM4000	40	18.5
	RM4001 above	27	12.5
	Not available	11	5.1

followed with items on the services received by parents and their children.

## RESULT

### Demographic Information of Parents/Guardians

Table I shows the demographic information of the parents/guardians. A total of 212 respondents were involved in this study, of which 104 (48.1%) were male

and 108 (50.0%) female, while 4 (1.9%) respondents did not state their gender. Majority of the respondents 70 (46.2%) were aged 31 - 40 years, followed by 69 (31.9%) aged 41 - 50 years and 49 (22.7%) aged 51 - 60 years. With regards to ethnicity, 146 (67.6%) were Malay, 56 (25.9%) were Chinese, 9 (4.2%) were Indians and 9 (2.3%) were of other races. Most of the respondents were parents of the children with disabilities 206 (95.4%) and others were grandparents, relatives or siblings.

With reference to highest education, a large number of respondents 75 (34.7%) had Malaysian Certificate of Education (O-Level equivalent), 58 (26.9%) had Middle Secondary Assessment certificates, 23 (10.6%) had diplomas, 22 (10.2%) had bachelor degrees, 4 (1.9%) had masters' degree or PhDs, three (1.4%) only completed primary school and 21 (9.7%) had no formal education. With respect to monthly income, the majority of respondents 89 (41.2%) earned less than RM1000, 49 (22.7%) earned between RM1000 to RM2000, 40 (18.5%) earned between RM2000 to RM4000, and 27 (12.5%), earned above RM4000.

**Table II Demographic Information of Children with Special Needs**

Item		n	f (%)
Gender	Male	128	59.3
	Female	86	39.8
	Not available	2	0.9
Age	6 to 12 years	151	69.9
	13 to 20 years	62	28.7
	21 years and above	3	1.4
Race	Malay	146	67.6
	Chinese	52	24.1
	India	8	3.7
	Aborigine	1	0.5
	Other	7	3.2
	Not available	2	0.9
Category of disability	Physical disability	8	3.7
	Visual impairment	4	1.9
	Hearing impairment	2	0.9
	Learning disability	198	91.7
	Not available	4	1.9
Education placement	Community-based Rehabilitation Centre	10	4.6
	Government schools	154	71.3
	Nonprofit center	27	12.5
	Private special education center	20	9.3
	Not available	5	2.3

## Demographic Information of Children with Special Needs

Table II describes the demographic information of the children. 128 children (59.3%) were male and 86 (39.8%) were female. In terms of age, 151 (69.9%) were aged 6 - 12 years, 62 (28.7%) 13 - 20 years, and 3 (1.4%) were 21 years and above. As for ethnicity, 146 children (67.6%) were Malay, 52 (24.1%) Chinese, eight (3.7%) Indian, one (0.5%) was of indigenous ethnicity and seven (3.2%) fell into the category of other ethnicities.

The largest category group of children in this sample were diagnosed with learning disabilities 198 (91.7%). Eight (3.7%) had physical disabilities, four (1.9%) had visual disabilities and two (0.9%) had hearing disabilities. When asked about the children's educational placement, ten children (4.6%) were educated in community-based rehabilitation centres, 154 (71.3%) in government schools, 27 (12.5%) in non-profit organization education centres and 20 (9.3%) in private education centres.

## Diagnostic Services Received by Children with Special Needs

Table III stated that 168 respondents (77.8%) mentioned that their children were diagnosed in government hospitals, 13 (6.0%) in government clinics, 18 (8.3%) in private hospitals and seven in private clinics. 75 children (34.7%) were diagnosed by general practitioners, 104 (48.1%) by medical specialists, 11 (5.1%) by therapists, and 15 (6.9%) by clinical psychologists. Vast number of respondents 183 (84.7%) stated that they received information and/or support as soon as their children were identified as having special needs compared to only 20 (9.3%) who stated that they did not receive any information.

The majority of respondents 163 (75.5%) stated that the service they received for diagnosis was either free or cost only RM1 (USD0.24). While 35 respondents (16.2%) stated they were charged "more than RM100" and 11 (5.1%) stated that they were charged "less than RM100". In response to the statement "How was the attitude of the medical officer who carried out the diagnosis/evaluation?", 204 respondents (94.4%) stated that the medical officer was responsible but only six (2.8%) said that the medical officer was not attentive in his/her duties. In response to the statement "In your opinion, did the medical officer use appropriate instruments when conducting the assessment and/or diagnosis?", 161 respondents (74.5%) stated "Yes" while 44 (20.4%) stated "No".

In response to the statement, "How long did it take for the medical officer to confirm your child's disability?", 69 respondents stated "less than 30 minutes", 67 (31.0%) stated "1-5 hours", 30 (13.9%) stated "1 week", 27 (12.5%) stated "1 month", and 3 (1.4%) stated "more than 1 month". In response to the statement "How many sessions did your child have with the medical officer

**Table III Diagnostic Services Received by the Child**

Item		<i>n</i>	<i>f</i> (%)
Where was your child diagnosed / evaluated as having special needs?	Government hospital	168	77.8
	Government clinic	13	6.0
	Private hospital	18	8.3
	Private clinic	7	3.2
	More than one answer	8	3.7
	Not available	2	0.9
What type of medical officer diagnosed / evaluated your child?	General practitioner	75	34.7
	Medical specialist	104	48.1
	Therapist	11	5.1
	Clinical psychologist	15	6.9
	More than one answer	6	2.8
	Not available	5	2.3
Was information and/or support given as soon as your child's disability was diagnosed?	Yes	183	84.7
	No	20	9.3
	Not available	13	6.0
How much were you charged by the hospital for diagnosis?	Free/RM1.00	163	75.5
	More than RM100	35	16.2
	Less than RM100	11	5.1
How much were you charged by the hospital for diagnosis?	Free/RM1.00	163	75.5
	More than RM100	35	16.2
	Less than RM100	11	5.1
	Not available	7	3.2
How was the attitude of the medical officer who carried out the diagnosis/evaluation?	Responsible	204	94.4
	Negligent	6	2.8
	Not available	6	2.8
In your opinion, did the medical officer use appropriate equipment when conducting the diagnosis/evaluation?	Yes	161	74.5
	No	44	20.4
	Not available	11	5.1
How long did it take for the medical officer to confirm your child's diagnosis?	Less than 30 minutes	69	31.9
	1 to 5 hours	67	31.0
	1 week	30	13.9
	1 month	27	12.5
	More than 1 month	3	1.4
	Not available	20	9.3
How many sessions did your child have with the medical officer before his/her diagnosis was confirmed?	Only one session	67	31.0
	Between 2 to 3 sessions	86	39.8
	More than 5 sessions	49	22.7
	Not available	14	6.5
How long did you wait in the clinic/hospital before you were able to see a medical officer?	Less than 30 minutes	45	20.8
	1 to 2 hours	135	62.5
	More than 3 hours	25	11.6
	Not available	11	5.1

CONTINUED

**Table III Diagnostic Services Received by the Child (CONT.)**

Item		<i>n</i>	<i>f</i> (%)
How long did it take you to get an appointment with a medical officer?	Less than 1 month	104	48.1
	1 to 12 months	64	29.6
	1 to 4 months	28	13.0
	More than a year	5	2.3
	Not available	15	6.9
What caused you to seek medical evaluation for your child?	Teacher /Counsellor / School administrator	43	19.9
	For placement into special schools	75	34.7
	Low academic achievement	34	15.7
	Behavioral problems	28	13.0
	More than one answer	12	5.6
	Not available	24	11.1
Were you satisfied with how the medical officer conducted the diagnosis/evaluate on for your child?	Yes	182	84.3
	No	20	9.3
	No response	14	6.5

before it was confirmed that your child has special needs?", 67 respondents (31.0%) stated "Only one session", 86 (39.8%) stated "Between 2 to 3 sessions", and 49 (22.7%) stated "More than 5 sessions". In response to the statement "How long did you wait in the clinic/hospital before you were able to see a medical officer?", 45 (20.8%) stated "Less than 30 minutes", 135 (62.5%) stated "1 to 2 hours" and 25 (11.6%) stated "More than 3 hours".

In response to the statement "How long did it take you to get an appointment with a medical officer?", 104 respondents (48.1%) stated "Less than 1 month", 64 (29.6%) stated "1 to 12 months", 28 (13.0%) stated "1 to 4 months", and five (2.3%) stated "More than a year". In response to the statement "What caused you to seek medical evaluation for your child?", 43 (19.9%) stated "Teacher / Counsellor / School administrator", 75 (34.7%) stated "For placement into special schools", 34 (15.7%) stated "Low academic achievement" and 28 (13.0%) stated "Abnormal behavioural problems". In response to the statement "Were you satisfied with how the medical officer conducted the diagnosis/evaluation for your child?", 182 (84.3%) stated "Yes" and 20 (9.3%) stated "No".

### Services and Support received by Parents of Children with Special Needs

In Table IV, 76 respondents (35.2%) stated "Yes" and 127 (58.8%) stated "No" when asked the questions "Have you ever participated in training / seminars / workshops / courses on how to educate your child?" 40 (18.5%) said that the seminar they attended was free while 29 (13.4%) stated that it was not.

With regards to the follow-up services received, 91 respondents (42.1%) stated that they received them

from medical doctors, 27 (12.5%) from counsellors, 49 (22.7%) from physical therapists, 55 (25.5%) from occupational therapists, 49 (22.7%) hearing therapists, 52 (24.1%) speech therapists, and 49 (22.7%) stated that they did not receive any follow-up service.

In response to the statement "Does your child receive any form of aid?", 172 (79.6%) stated that they do and 44 (20.3%) stated that they do not. Among the types of aid received, 130 (60.2%) received disability allowances, four (1.9%) received wheelchairs, four (1.9%) received artificial limbs, 15 (6.9%) received skills training, and 19 (8.8%) received medications.

In response to the statement "What do you hope for in your child's future?", 69 respondents (31.9%) stated "To attend school like other children", 87 (40.3%) stated "To receive vocational training", 132 (61.1%) stated "To have a job and be independent" and 31 (14.4%) stated "To enter community-based centres".

### DISCUSSION

Majority of the parents or guardians reported that they seek diagnostic service for their children after being advised by school personnel such as teachers, counsellors and/or administrators. Oftentimes, parents were advised to get a diagnosis for their children after school personnel noticed developmental issues with the children, a need for the children to be placed in special education class, the children's behaviour problems and the children's low achievement in school. This scenario suggests that these children were only identified after entering formal primary education, which highlighted the fact that there is a lack of early identification effort to screen children with developmental issues in Malaysia. This scenario also implies that parents were not aware

**Table IV Support and Services received by Parents of Children with Special Needs**

Item		<i>n</i>	<i>f</i> (%)
Have you ever participated in training / seminars/ workshops / courses on how to educate your children?	Yes	76	35.2
	No	127	58.8
	Not available	13	6.0
If yes, was the seminar free-of- charge?	Yes	40	18.5
	No	29	13.4
	Not available	147	68.1
Does your child receive follow-up services from the following officials?	Medical doctor	91	42.1
	Counsellors	27	12.5
	Physical therapists	49	22.7
	Occupational therapists	55	25.5
	Hearing therapists	49	22.7
	Behavioral therapists	33	15.3
	Speech therapists	52	24.1
	No service received	49	22.7
	Medical doctor	91	42.1
Does your child receive follow-up services from the following officials?	Counsellor	27	12.5
	Physical therapists	49	22.7
	Occupational therapists	55	25.5
	Hearing therapists	49	22.7
	Behavioral therapists	33	15.3
	Speech therapists	52	24.1
	No service received	49	22.7
	Medical doctor	91	42.1
Does your child receive any form of aid?	Disability Allowance	130	60.2
	Wheelchairs	4	1.9
	Artificial limbs	4	1.9
	Skills training	15	6.9
	Medications	19	8.8
	No aid received	44	20.3
What do you hope for in your child's future?	To attend school like other children	69	31.9
	To receive vocational training	87	40.3
	To have a job and be independent	132	61.1
	To enter community-based center	31	14.4

of their children's developmental issues as they needed to be alerted of their children's condition by school personnel.

Failure to identify a child's disability or developmental issues as early as possible means a delay in early intervention provision and its benefits, such as ensuring a child's optimal development, arrest of further negative impact of the disability and parent empowerment (15). Therefore, this issue of late identification of children with disabilities must be investigated further in order to improve the situation. One of the strategies to promote early identification of children with disabilities is to heighten the awareness of this issue among parents (16,17).

This study included mainly parents of low socioeconomic status. As such, it is not surprising that they mainly access government health facilities to get their children assessed for a diagnosis as the service is very affordable costing RM1 or less. Affordable health system is a strong point of the country (18,19). Majority of the parents reported that they were satisfied with the medical officers carrying out the diagnostic process which had a short waiting time for an appointment. However, one cause of concern was the fact that only slightly less than half of the children in this study were diagnosed by medical specialists. A considerable number of them were diagnosed by general practitioners and a small number was even diagnosed by therapists. Majority of the children were diagnosed with a learning disability but more than half of the parents stated that the medical officers took less than half an hour to confirm their children's diagnosis and a third of the parents shared that it only took one session to confirm their children's diagnosis. This is a matter of concern as to produce a diagnosis of disability for a child, a specialist needs to run a few batteries of tests and assessments including an in-depth observation of the child.

The issues in diagnosing children with learning disabilities in Malaysia has been highlighted before (12), which include the lack of standardized and culturally sensitive measurements and limited number of professionals with specialized training in the diagnosing process. Therefore, it is highly recommended that future research be undertaken to investigate alternatives to diagnostic tests of children which is clinical-based, to school-based, curriculum-based assessment i.e. Response to Intervention (20).

Another major issue highlighted by the findings of this study was the fact that support and assistance did not reach all the parents and children post diagnosis. Although the majority of respondents stated that they were given support and information, 20% claimed that they had not received any support at all. Only 60% of the respondents claimed that their child received the disability allowance which is the right of any child with



disability. Another worrying issue is that 22% of the respondents reported that their children did not receive any follow-up treatments of any kind.

In terms of training for parents, only one third of the respondents reported that they had attended training on how to support their children. And most worrying of all is that only 71% of the children in this study were enrolled in government schools.

This study has managed to highlight several issues that arose post diagnosis of these children. These issues call for further research in order to help all stakeholders to have a better understanding of the existing barriers which resulted in some parents and children not receiving support and assistance.

Given that the current study was a preliminary in nature, few limitations are acknowledged. For instance, the data analysis for this study was mainly descriptive which did not yield to any statistically significant results. A much clearer understanding of the experiences of parents of children with disability during and after their children's diagnosis would have been achieved if a deeper analysis was implemented. For example, a correlation analysis might have suggested some insights on the relationship between parents' satisfaction of the diagnostic process, medical personnel and support received and with their social economic status and child's category of disability. Thus, the future research which examines these relationships is highly recommended.

Next, the instruments used in this study was mainly a survey instrument developed by researchers to understand the nature of early experiences in diagnosis. The arbitrary design of questionnaires and multiple-choice questions with preconceived categories might represent a biased and overly simple view of reality and often doesn't capture a full range of expression from the respondents. Thus, it is highly recommended for future research to have more comprehensive and standardized tools. The more in-depth information regarding the experiences and processes also can be obtained through interviews with parents.

Also, the participants recruited in this study was a convenience sample where it might not produce representative research findings. Thus, it is highly recommended for the future study to utilize a probability sampling to increase the equal opportunity of the individual in population to be selected as a representative sample and obtain a higher level of reliability of research findings.

## CONCLUSIONS

Despite the limitations, this study has a few strengths; namely, the findings of the current study have provided preliminary groundwork for further research on experiences of parents related to the diagnosis of their

children with disabilities and actions to be taken by the policymakers and practitioners.

The main findings in this study suggest that there are some issues in the process of diagnosing the disabilities, lack of a comprehensive early identification system and neglected needs of parents for support and assistance post diagnosis. Therefore, further investigations are strongly recommended in looking for alternatives: curriculum-based identification of certain disabilities, especially learning disabilities; a non-clinical based early identification system via parents and preschool; and parents' empowerment efforts through education and training.

Though preliminary in nature, this study has managed to pave for a good understanding of issues in diagnosing disabilities among children in Malaysia. It has the potential to kick start further investigations into the efforts in early identification which hopefully will lead to a formation of a comprehensive early intervention system and parent empowerment for the benefit of children with disabilities in this country in the long run.

## ETHICAL CLEARANCE

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